

**The development and evaluation
of a community-based programme
offering psychosocial support to vulnerable children
affected by HIV/AIDS, poverty and violence.**

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Declaration

This study represents original work by the author and has not been otherwise submitted in any form for any degree or diploma to any university. Unless otherwise stated, I hereby declare that this thesis is my own work.

B J Killian

This dissertation is being submitted for examination with my approval.

Supervisor: Professor Kevin Durrheim

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Abstract

This research programme endeavours to develop, implement and evaluate an effective method of offering psychosocial support to vulnerable children. Vulnerability is defined by trained community members as including children who are experiencing especially difficult lives. The forms of difficulties experienced by the children has usually been a consequence of the HIV/AIDS pandemic, extreme poverty combined with other psychosocial risk factors, child abuse (especially child sexual abuse) and violence. This community based programme incorporates four phases of intervention, only two of which were the focus of summative evaluation. However, due to the integrated nature of the programme it was necessary to implement and document the various phases of the intervention programme: (i) community selection and mobilisation; (ii) the 5-day Sensitisation Programme (SP) sensitises adult community volunteers to the psychosocial needs of vulnerable children; (iii) the 15-session Structured Group Therapy Programme (SGTP) enables children to work through past adversities and to build resilience within small groups of peers in a programme where community volunteers served as apprentice facilitators under the supervision, guidance and ethical responsibility of qualified psychologists; (iv) community based initiatives to offer on-going of PSS activities to vulnerable children in each of the partnering communities. Nine partnering communities were selected, three township, peri-urban and rural communities. This programme was not effective in the informal settlements as it was not possible for these communities to place children as a priority.

A qualitative summative evaluation of the SP took place using post workshop evaluation questionnaires, focus group discussions conducted by an independent researcher and an audit of the community based initiatives that developed as a result of participation in the SP. The SGTP was summatively evaluated using a 4-way Factorial design with one within-subject and three between-subject conditions: to investigate the age of the subjects, the geographic regions and gender variables. The 741 children formed five experimental and control conditions to conduct various combinations of the above-mentioned phases programmes and to adequately control for the many confounding variables. Pre- and post intervention assessments were conducted by trained community research assistants. The dependent variable measures were the Culture Free Self Esteem Inventory (Battle, 1992), the Trauma Symptom Checklist for Children (Biere & Elliot, 1997), the Reynolds Depression Scale for Children (Reynolds, 1989), the Social Support Scale (Beale Spencer, Cole, Jones, and Phillips Swanson, 1997) and the Connor's Parent Questionnaire (Connors, 1998). Multivariate analysis evaluated the effectiveness of the various experimental and control conditions. The results indicate that the SGTP, run in combination with the SP, is an effective intervention strategy in that it alleviates symptoms of self-reported depression and other psychosocial manifestations of distress as well as decreased the number and severity of symptoms reported by primary caregivers, and leads to increased access to perceived social support. The SP and the SGTP conducted independently of each other have limited benefits and as such can be considered to be partially effective. The children who had formed part of the non-vulnerable control group felt left out of the programme and report an increase in symptomatology and decreased access to social support. While this community-based programme can be considered to be an effective method of therapeutic intervention and of offering psychosocial support to vulnerable children, further research is needed to consider the cost-effectiveness, the sustainability and ways in which those children who do not participate can still benefit.

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AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Treatment/Therapy
ATP	Apprenticeship Training Programme
CBO	Community-based Organisation
CRC	UN Convention on the Rights of the Child
FBO	Faith-based organisation
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
HIV+	Infected with the Human Immunodeficiency Virus
HIV-	Seems to be free of the Human Immunodeficiency Virus
MTCT	Mother to Child Transmission
MVA	Motor Vehicle Accidents
NGO	Non-Government Organisation
NPO	Non-Profit Organisation
OAU	Organisation for African Unity
PAR	Participatory Action Research
PS	Psychosocial
PSS	Psychosocial Support
PLWA	People living with HIV/AIDS
SP	Sensitisation programme for community volunteers offering psychosocial support to vulnerable children
SS	Social Support
SSS	Social Support Scale
SGTP	Structured Group Therapy Programme for Vulnerable Children
UNGASS	United Nations General Assembly Special Session on Children (2001)

Chapter 1

Overview of the Research Programme and Definition of Terms

1.1. The Basic Research Issues:

HIV/AIDS is the leading cause of death in sub-Saharan Africa (Shisana & Simbayi, 2002). It has already claimed more than 20 million lives and generated an estimated 43 million orphaned children in sub-Saharan Africa (Hunter & Williamson, 2002; USAID, 2004). There is little doubt that the AIDS crisis can accurately be described as the “greatest social disaster in Africa since slavery” (AIDS Conference, 2000), inflicting economic, social, familial and personal destruction in its path. The challenges are enormous. Most theories of child development would predict major social and psychological devastation in reaction to such unprecedented psychosocial risks. Therefore, it becomes critically important that the psychosocial repercussions of HIV/AIDS on children, families and communities be examined, understood and appropriate interventions developed. The contextual variables need to be explored, so that armed with this information, effective intervention programmes can be developed to mediate the psychosocial risks faced by these vulnerable children.

In the 20 years since HIV was first identified, there has been an incremental increase in the nature and form of programmes aiming to address the many problems that are emerging as a result of this pandemic (Germann & Madörin, 2002). Much of this work has taken the form of frontline responses, in which mental health and community workers struggle to address the impact of the virus on individuals, families and communities. There has hardly been time for reflection on underlying theory and principles, or to engage in systematic evaluation of programmes. Innovative and resourceful strategies have been implemented as people frantically scramble to tackle the problems as they emerge, evolve and multiply. Much sterling and effective work has already been undertaken. However, many mistakes have been made and lessons have been learnt.

The two most pervasive criticisms that can be levelled against the frontline reactions are (i) the lack of theoretical grounding that has led to piecemeal interventions that unfortunately are, by their very nature, doomed to be limited in their impact and effectiveness; and (ii) the paucity of evaluation and/or critical reflection on many of these interventions (Phiri, Foster, & Nzima, 2001; Williamson, 2000).

Psychology, as a discipline, provides theories of child and community development which could usefully inform the development of appropriate intervention strategies. The ecological theories of child development stress the significant role of contextual and systemic variables that expose children to risk and resilience factors, which in turn influence the developmental trajectory for children and their communities. The theories of community development emphasise the need for community ownership, capacity building, empowerment and sustainability for all meaningful and effective interventions (Duffy & Wong, 2000).

Given the probability that up to 35% of all children may be orphaned in some sub-Saharan countries

by 2020 (Germann & Mäddörin, 2002), the situation of children affected by HIV/AIDS needs to be recognised as both a long term and large scale problem requiring strategies geared to these realities. This eliminates the feasibility of many of the more orthodox, individually-based, child intervention strategies. For an intervention programme to be relevant in the current circumstances, it must be accessible to large numbers of children, take into account the numerous and accumulative impact of psychosocial risks, be sustainable and cost effective¹ (Hunter & Williamson, 2000, 2002; Germann & Mäddörin, 2002; UNICEF, 1999). Interventions also need to recognise that children are not the problem but are part of the solution, as they actively bring their own unique competencies, skills, perceptions and energy to the arena.

HIV/AIDS is most prevalent in the poorest communities (Hunter & Williamson, 2002; Snider, 2004; Stein, 2003; Taylor, Adelzedak, Heywood, January-Bardill, Abdool Karim, Magadlala, Pendry, Vilikazi, & Whiteside, 1999; UNICEF, 1999; Wild, 2001), in which other poverty-related illnesses (e.g. tuberculosis, malaria, and gastro-enteritis) are endemic. These increase the number and severity of opportunistic infections that in turn exponentially increase mortality rates. In addition, many sub-Saharan African countries have experienced prolonged political repression, struggle, violence and discrimination leaving the communities impoverished, fragmented and struggling for basic survival (Higson-Smith & Killian, 2000).

From the child's perspective, the prolonged illness and death of one or both parents or primary caregivers is a dramatic and terrifying process. They lose the love and care of their primary attachment figures, their family stability and their identity. Their young lives are made miserable by a conglomeration of adverse social circumstances and associated risk factors:

- Caring for sick family members followed by multiple loss experiences as parents, siblings, other family members, friends and neighbours die.
- Dislocation from nuclear and extended family, as well as one's cultural roots could jeopardise the development of one's own identity, leaving children feelings as if they do not belong, alienated from themselves and others.
- Ostracism and discrimination as a result of being a member of a family that is HIV infected. Stigmatisation occurs at all levels of societal functioning and denies children access to various social structures and institutions. The stigma associated with HIV/AIDS brings shame, embarrassment, fear, rejection, and other forms of psychosocial distress that exacerbate the anguish of the children and their families.
- Loss of parental income leads to a lack of economic resources with a concomitant loss of educational opportunities and health care.
- Increased risk of victimisation through child abuse and neglect.
- Increased age-inappropriate responsibilities and labour - with the potential for exploitation

¹ Cost effectiveness is a key criteria as it refers to both the maximal utilisation of limited financial resources, as well as a need for rapid sensitising, enskilling and capacity building in the skills required to work effectively with vulnerable children and their communities (Germann, 2003). However cost-effectiveness lies outside of the realm of this dissertation.

of this vulnerable sector of the population.

- Compromised health and possible malnutrition.
- Greater risk of HIV infection and other poverty-related diseases (Hunter, 2002; Hunter & Williamson, 2000; Phiri et al., 2001; Wild, 2001).

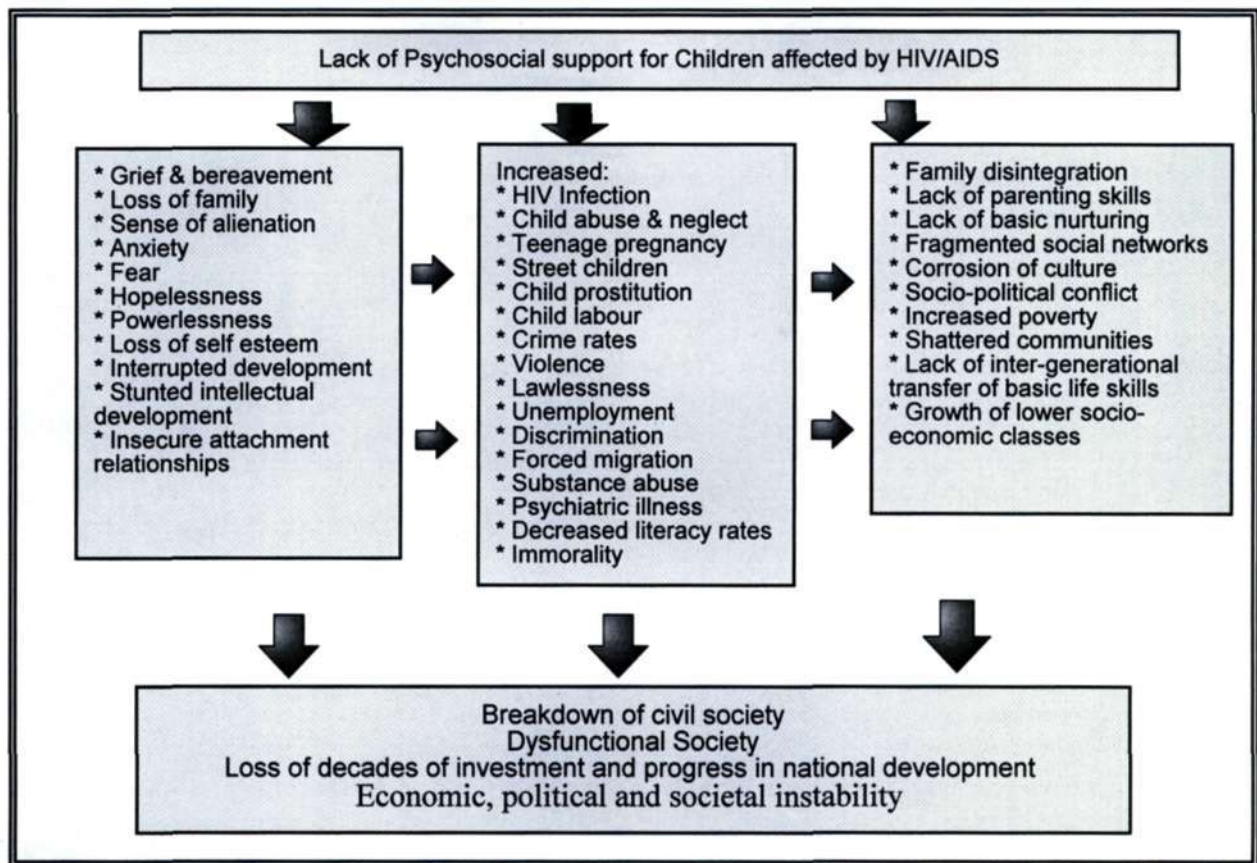
These harsh life circumstances jeopardise children's development. A child's extreme distress can predictably lead to low self esteem, hopelessness, anxiety, aggression, depression and other behavioural, cognitive and emotional problems (Hunter & Williamson, 2000; Stein, 2003; Stein, Fonagy, Ferguson & Wisman, 2000). Complicated bereavement is a probable outcome in these adverse circumstances. The problems most frequently associated with these psychosocial risk variables are behavioural and emotional dysfunction, stunted intellectual development, inadequate communication and life skills, and poorly developed problem solving, decision-making and conflict resolution skills (Germann & Mäddörin, 2002; Sroufe, 1997; Smith & Carlson, 1997; Rutter & Quinton, 1984; Stein et al., Werner, 1984).

These probable consequences jeopardise personal development as well as the foundations of strong families, communities, and even entire nations for future generations (Germann & Mäddörin, 2002; Schönteich, 2002). The accumulative impact of these multiple psychosocial risks statistically predicts that children growing up in circumstances of adversity are likely to experience significant difficulties. The theories of risk and resilience (Rutter, 1999, Smith & Carlson, 1997; Sroufe, 1997; Werner, 1984) indicate that the experience of multiple psychosocial risk factors can have clear, long term, negative developmental impact. Unless children are offered psychosocial support, their emotional and social experiences may manifest in various social problems, that could lead to major social instability and even to a breakdown of civil society (See Figure 1.1).

It is also important that intervention programmes acknowledge the natural resilience of many children, their numerous and diverse strengths, and normal developmental and culturally-defined needs. The 'pathologising' of vulnerable children can subtly, yet decisively, stigmatise them and undermine their self esteem, their strengths and their resourcefulness. This would be unethical and would sabotage the success of the programme (Dawes & Donald, 2000).

Resilience is not a finite quality that some individuals have while others lack it but rather that resilience can be strengthened, mediated, developed and taught to ameliorate against the impact of psychosocial risk (Mallman, 2002; Masten, 2001; Smith & Carlson, 1997). Therefore, the challenge is to develop appropriate strategies to meaningfully alter the developmental trajectory from one of a dismal future fraught with difficulties, to a path of hopefulness, adaptiveness and mental health.

Figure 1.1.: Potential long term impact of poor PSS for children affected by HIV/AIDS:



Adapted from: Regional Psychosocial Support Initiative (2001). *First Regional Think Tank on Psychosocial Support for children affected by HIV/AIDS*, Masiye Camp, Zimbabwe, p. 16.

1.2. An overview of the research process:

The focus of this psychosocial intervention programme required mobilising and enhancing the individual and community resources within partnering communities. The objective of the intervention was to facilitate coping, provide sensitive psychosocial support, promote positive self-esteem and build resilience in a sustainable and empowering manner. In addition, there is a need to assist children to manage and regulate the negative thoughts, feelings and behaviours that had been provoked by distressing life experiences. To achieve these goals, there is a fundamental need for at least two units of intervention: child/personal and community/environmental (Smith & Carlson, 1997). Therefore the objectives for this community-based intervention strategy were two tiered:

1. The intention with respect to the *community* was to facilitate community mobilisation around the issue of vulnerable children; to sensitise key stakeholders to the psychosocial needs of vulnerable children; and to develop the capacity of some community members to work effectively, on a volunteer or employed basis, with vulnerable children.
2. The objective in terms of *vulnerable children* was to enable them to therapeutically work through the emotional repercussions of the major life stressors that they had experienced; to promote resilience through developing positive self esteem and competencies; and to assist children to develop problem solving and appropriate help-seeking behaviours.

A third focus area, not a primary focus of the programme evaluation, involved the apprenticeship training of facilitators who could eventually conduct the programmes independently of the researcher. The aim in this regard was to enskill members of the community and personnel from key NGO's/CBO's already working or wishing to begin working in partnering communities to implement the intervention. It was hoped that these people would be trained in initiating, implementing and sustaining a community's commitment to offer ongoing PSS to their vulnerable children. After mobilising a community around their vulnerable children, community members and workers participated in a Sensitisation Programme (SP) that would enable them to become compassionate, confident and willing to help vulnerable children. They could then elect to be trained in conducting the Structured Group Therapy Programme (SGTP) in a responsible, ethical and effective manner using an apprenticeship model of training. The capacity building aspect at the community level required additional support, monitoring and supervision which falls beyond the scope of the current research programme. Nevertheless, the process was initiated and will be documented at a later stage.

Consequently, this research programme has two interdependent research contexts, which for ease of analysis and evaluation will be treated sequentially:

- (1) High HIV/AIDS prevalence *communities*, from different geographic areas, were selected and a community mobilisation programme was conducted in each of these nine partnering communities. When adult members of the partnering communities requested training, the Sensitisation Programme (SP) was conducted in order to raise their awareness and knowledge of the psychosocial needs of vulnerable children. This Sensitisation Programme (SP) (Killian, Schoeman & Hough, 2002) became the subject of a qualitative evaluation. For ease of reading the material, all aspects of this evaluation will be presented in Part 3 of this dissertation - including the methodology, results and discussion sections.
- (2) The most *vulnerable children* (as identified by trained community members) resident in the partnering communities participated in the adapted Structured Group Therapy Programme (SGTP) (Killian, 2002) under a variety of experimental and control conditions in order for a summative evaluation of the effectiveness of this programme to be conducted. To help the reader follow sequential ideas and concepts, all aspects of this evaluation will be presented in Part 4 of this dissertation - including the methodology, results and discussion sections.

The interdependence of these components is considered axiomatic to the development and implementation of the programme, even though in terms of evaluation, they are treated as discreet entities (See Figure 1. 2). Obviously various intermediate steps were required for this intervention to be possible. Much of the preparatory work did not form part of the current evaluation *per se*, and so will be documented in brief, protocol format. In developing, implementing and evaluating this holistic, community-based intervention programme, the units of analysis are complimentary and interdependent - children live in communities, and communities have concerns for and responsibilities towards their children. Any sustainable intervention at a community level requires training, enskilling, capacity and confidence building amongst community members to enable them

to sustain the intervention. Community participation and empowerment were integral aspects of the programme. They required participatory action research (PAR) methodologies to explore community-based conceptualisations and definitions of some of the key concepts.

Therefore, the aim of this research programme was to evaluate the effectiveness of a programme that aimed to address the psychosocial needs of vulnerable children living in high prevalence HIV/AIDS communities. Although highly ambitious and considerably more complex than most research programmes, it was strongly believed that should segments of the programmes be partitioned-off and excluded, this would in effect retrogress the programme to being simply a piecemeal intervention strategy. The very nature of the pandemic and the way in which it impacts on the well-being of individual children, families and communities demands a multi-faceted, community-based intervention. In turn this necessitated ambitious research methodologies to evaluate the effectiveness of this intervention programme.

When selecting the evaluation procedures through which to address the research question, a number of options were open to the researcher. The selection of methodological procedures involved the researcher "from unconscious worldview to enactment of that world view via the inquiry process" (Guba & Lincoln, 1989, p. 183). The entry phase for this research involved a survey of the available literature followed by an articulation of an appropriate workable perspective (Packer & Addison, 1989). The latter required the researcher to make explicit a set of axiomatic principles upon which she developed the intervention programme. In essence, this represents the researcher's perspective of what she considered to be the essential components of an appropriate response to the research question.

The process of programme development was complex in that it was an attempt to develop a holistic, community-based intervention programme that operates at both community and child levels. In collaboration with colleagues and drawing on available programmes and literature, the researcher developed two intervention programmes in manual form. The training programmes aim to (i) sensitise community members to the psychosocial needs of vulnerable children - the SP (Killian, Schoeman & Hough, 2002); and (ii) present a structured group therapy programme for vulnerable children (SGTP) (Killian, 2002).

Attempts were made to expedite the building of consensus on the most appropriate intervention strategies by circulating drafts of these two programmes to psychologists and community workers for review. Potential consumers of the intervention programmes were included in the review process in order to draw on their unique and extremely relevant areas of expertise. The consultations with community members around the appropriateness of the programmes formed an integral part of a community mobilisation process. Indeed a prolonged period of community mobilisation preceded the implementation of the training programmes which form the heart of this thesis.

The programme evaluation phase forms the essence of this dissertation. The social sciences are pre-eminently 'evaluative' disciplines that have provided the methodologies and insights with which to launch evaluations of intervention strategies (Patton, 1990). Productive programme evaluation provides actionable advice as well as evidence of effectiveness and achievements, based upon rigorous analysis of data. Programme evaluation is considered to be critical in terms of providing evidence of the effectiveness, or otherwise, of the programmes and indicating areas that require improvement. This holistic community-based intervention programme called for multi-faceted evaluations:

- (1) Participatory action research techniques were used to mobilise communities on the issue of their vulnerable children and to explore community-based conceptualisations of the key concepts used in this intervention. It was also important to document the contextual variables that characterise the communities, all of which are situated within South African's most rural province, KwaZulu Natal, at a time of socio-political transition and the HIV/AIDS pandemic;
- (2) Formative in that it evaluates the programme implementation. Formative evaluation is also an ethical requirement of research that uses human subjects.
- (3) Summative in that the effectiveness of the programme was evaluated using various qualitative and quantitative procedures. These evaluations formed the primary focus of this research study.

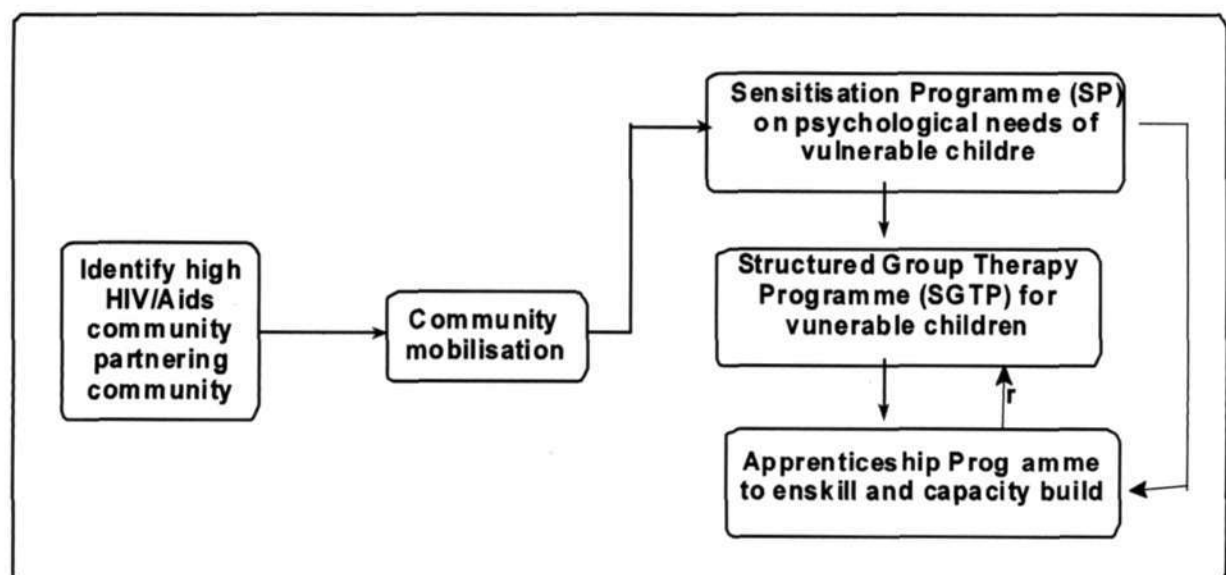
1.3. Defining Key Terms:

Before proceeding with an exploration of the nature and scope of the problem and a review of the relevant literature, the remainder of this chapter will be devoted to defining some of the key terms.

1.3.1. Children and Childhood:

It is opportune at this early stage, to define the terms children and childhood. In the absence of generally sanctioned definitions of these terms, most especially in communities where the western ideas of childhood are constantly being challenged, special consideration of these terms is required.

Figure 1.2.: Overview of the intervention.



Concepts of childhood are cultural constructs, with the defining characteristics varying across cultures and situations. Those features that are readily used to define childhood from a western perspective, do not necessarily apply across cultures and circumstances. Factors such as age, developmental immaturity, financial dependency, degree of responsibility or blameworthiness are not universally accepted as the defining characteristics of childhood (Kelly, Ntlati, Oyosi, van der Riet & Parker, 2002). Moreover, the construct of childhood is undergoing rapid re-definition in the context of the HIV/AIDS pandemic.

Nevertheless, there is a universal need to acknowledge that children need the assistance of adults (UNICEF, 1989). They need primary caregivers to give them emotional and social support and direction. Any intervention strategy that aims to address the needs of vulnerable children must take into account the prolonged dependency state of the human species. The process of socialisation, by definition, is embedded within a social context that includes adult members of a community.

One can consider the concept of childhood from the inverted perspective of the special obligations, commitments and responsibilities that societies, in the form of its adult members, need to shoulder in order protect their children (Kelly et al., 2002). The political history of South Africa has challenged western definitions of childhood in that widespread poverty, in combination with the various policies of the *apartheid* regime, severely discriminated against black children, and changed the face of childhood for black children in this country (Donald & Dawes, 1994; Mbambo & Msikinya, 2003). South African society is in a rapid state of transformation. However, both during the *apartheid* era as well as presently, black children have generally experienced formidable and tenuous lifestyles. During their young lives, many have struggled for their physical, emotional and social survival and stability. Given this history, researchers need to be cautious. Firstly, one must avoid the hardships and asperity of previous generations of black children. Secondly, one must be careful not underestimate children's resilience and coping abilities

The children's rights perspective (OAU, 1994; UNICEF, 1989; Constitution of the Republic of South Africa, 1996) defines a child as someone who is below the age of eighteen years. No distinction is made between a prepubescent child (conventionally regarded as a child under the age of 12 years) and a child who has developmentally passed through puberty but has not yet attained legal majority status (children conventionally referred to as adolescents or youth).

In this research programme, a child was defined as anyone under the age of 18 years, for the specific purpose of drawing attention to children and adolescents who are (i) heading households, (ii) the primary caregivers for terminally ill parents and relatives; and (iii) being denied their basic children's rights either by taking on adult responsibilities, or through discrimination, lack of facilities and inferior access to social services. However, the Structured Group Therapy Programme (SGTP) was conducted with latency aged children (within the 8 to 12 year age range). If the programme proves to be effective, it could be adapted to suit adolescent and pre-primary children. The SGTP is

intended for two age groups of children: eight to ten year old children and ten to twelve year old children, corresponding with different cognitive developmental stages (Aber, Gephart, Brooks-Gunn & Connell, 1997) for the primary school child. The rationale for this age-range selection is based on the relative ease with which children in this stage of development can engage with the therapeutic process (Guerney, 1979, in Schaefer & O'Connor, 1983), and the epidemiological factors that suggest that this age group have the greatest chance of survival through the HIV/AIDS epidemic (Shisana & Simbayi, 2002).

1.3.2. Rationale for the focus on vulnerable children:

This research programme aims to address the psychosocial needs of vulnerable children. The cumbersome and all-encompassing term 'vulnerable children' replaces the numerous, at times stigmatising and confusing, terms that are more frequently used in the literature: orphans and other vulnerable children (OVCs), children affected by and infected with HIV/AIDS (CABA), children in distress (CINDI), children experiencing orphanhood, etc. These terms fail to recognise that orphanhood is part of a much larger crisis and process. Countries that have high rates of orphaning due to AIDS, also have high rates of children seriously impacted by the epidemic (Hunter & Williamson, 2002, p. 11). Extended families are the social institutions that most frequently 'take in' orphaned children. This directly affects other children in extended family households, where the physical, financial and emotional resources may already be scarce (UNICEF, 1999).

The western and legal concepts of orphans, as well as the definitions favoured by the large International Agencies (such as UNICEF, UNAIDS and USAID), define orphans as children whose biological parents have died. These definitions fail to take into account cultural concepts of orphanhood (Giese, Meintjes, Croke & Chamberlain, 2003). Being termed an orphan in many African communities would signify that there is no-one who cares for or about the child. So in the African context, a child whose parents are deceased, but cared for by relatives or community members, is not traditionally considered to be an orphan. In fact, referring to a child as an orphan could bring shame and disgrace to the family (Cook, 1998), and even to the community in which the child lives, who could be perceived as failing in their duty towards children (van Dyk, 1999).

The Draft South African Children's Bill (2002) defines an orphan as "a child ... who has no surviving parent caring for him/her after one or both of them has died or abandoned him/her" (p.29). This definition still fails to take into account the immense vulnerabilities that children commonly face prior to the death of their parent/s (Giese et al, p. 14). Furthermore, it fails to acknowledge the multiple child care arrangements operative in sub-Saharan Africa (Cook, 1998). Many African children are not raised by a single attachment figure and very few are raised within a nuclear family (Barbarin & Richter, 2001a; Mbambo & Msikinya, 2003). Rather, due to the communal nature of African society and various socio-economic considerations, children are likely to experience a sequence of different caregivers. Even before the HIV/AIDS pandemic, there was a trend for them to be exposed to various care arrangements: the primary caregiver may change as children enter each developmental stage (for example, living with grandparents in infancy, moving from a rural to a peri-

An overview of the thesis layout

The basic research issue involved an evaluation of two elements of a multi-tiered intervention programme, which aimed to offer psychosocial support to vulnerable children living in communities in which they were exposed to multiple risk factors, including HIV/AIDS, poverty and violence. The two elements that are of prime consideration involve inter-related units of analyses: the community and vulnerable children. The community level of intervention was an acknowledgment of the context in which vulnerable children live and recognises that children need psychosocial support and care from adults. The child level of intervention involved offering the most vulnerable children structured group therapy. In order to do justice to the programme it was essential to situate these two critical elements within the holistic intervention programme, by implementing the total intervention within selected partnering communities. This creates a dilemma in terms of writing this dissertation within the prescribed format. Some creative liberty has been taken in ordering the various sections of the thesis in a manner that enables the reader to follow this multi-tiered process as logically as possible. There are six sections in this dissertation:

Section 1 has been divided into five chapters. Chapter 1 consists of an overview of the research issues and definitions of key concepts. The AIDS pandemic is outlined in Chapter 2 with regard to epidemiological factors and general issues that are likely to directly impact on children's well-being. The psychosocial impact of the HIV/AIDS pandemic on children's psychosocial functioning is covered in Chapter 3.

Section 2 focuses on the literature pertaining to children who are exposed to adversity. The theories of risk and adversity combined with the coping and resilience literature provide useful insights both in terms of the impact of the adversities to which children in high HIV/AIDS communities are exposed as well as strategies that can enhance their coping, build resilience and develop self esteem (Chapter 4 and 5).

Section 3 introduces the holistic programme of intervention and lays the ground for the two critical aspects of the intervention programme to be implemented and evaluated. Armed with knowledge of the nature and scope of the problem, and the theoretical foundations which could inform an intervention, the researcher addressed the question of what would be the most expedient and effective modality of intervention (Chapter 6). Guided by the literature, several axiomatic conditions were established and became the guiding principles for all aspects of the work. Chapter 7 outlines the participatory action ethic that was adopted throughout the intervention/research programme, considers some of the basic issues related to ethics, validity, translation and cross-cultural research, explains the process of selecting and surveying the partnering communities, and presents the community profiles to provide the reader with a sense of the context in which this research was conducted.

Section 4 presents the methodology, results and discussion with respect to the evaluation of the Sensitisation Programme (SP), in two chapters. Chapter 8 presents the methodology to evaluate the effectiveness of the SP as a community-level intervention and Chapter 9 gives the results and discussion of this aspect of the evaluation.

Section 5 covers the summative evaluation of the Structured Group Therapy Programme (SGTP) with the methodology being explained in Chapter 10, and the results presented and discussed in Chapter 11.

Section 6 provides critical reflection on this research study and provides a summary of the results, in relation to the stated hypotheses (Chapter 12 and 13).

SECTION 1

Introduction

The nature and scope of the pandemic

The impact of the pandemic on children's psychosocial functioning

Theoretical review of the concepts of risk and resilience.

urban area for primary schooling, to an urban area for secondary schooling); many have been raised without paternal figure (who have sought employment in other provinces and towns)s; separated from biological siblings; and so forth (Giese et al., 2002).

The HIV/AIDS pandemic severely impacts on the shape and form of households, as well as on vulnerability and coping strategies. In their research programme, Giese et al. (2002) used the term “children experiencing orphanhood” to include children in the care of HIV+ caregivers; children living with caregivers/breadwinners who have HIV/AIDS or who are very sickly; children living without parents; children living with younger siblings; children who are cared for informally by relatives or others subsequent to the death of their biological parents (i.e. not legally fostered or adopted); children in the care of one remaining parent after the other has died; children living on the streets; and children in residential care (p. 15). These are the situations in which many of the children who form the focus of this study live.

In this dissertation, the use of the term “vulnerable children” recognises that children are affected in multiple ways by the HIV/AIDS pandemic, and nearly all children living within a high prevalence HIV/AIDS community are probably vulnerable and have been exposed to a multiplicity of psychosocial risk factors. It was envisaged that children identified by community members as being especially vulnerable would include those whose care had been compromised (i) through the death of a biological parent/s; (ii) the death of an adult, other than a biological parent, who contributed substantially to the care and/or financial support; (iii) by living with a terminally ill adult who contributes to the care and/or financial support of the child (Giese et al., 2002, p. 14) and (iv) children who were being exposed to especially adverse life circumstances (including those who live in circumstances of substance abuse, domestic violence and child abuse and neglect - these issues being integral to community-based definitions of vulnerability. The term vulnerable children takes into account the various risk factors associated with the HIV/AIDS pandemic as well as two other major adversities that impact on children: extreme poverty and a prolonged history of political discrimination and violence. Most poverty-stricken children experience victimisation, stigmatisation, discrimination, poor schooling, and inadequate access to resources. The term ‘vulnerable children’ conveys a belief that many children living in high prevalence HIV/AIDS communities are in need of psychosocial support.

The focus on vulnerable children also avoids stigmatising affected or infected children and the unnecessary reinforcement of discrimination within high prevalence communities. The proliferation of myths and mis-information about HIV/AIDS requires special sensitivity to the dynamics of an affected individual, family or community. An essential ethical principle is that all forms of stigmatisation and discrimination are to be stringently avoided (Clacherty & Associates, 2001). The mere act of labelling and targeting a child for an HIV/AIDS intervention can constitute a psychosocial risk, be an infringement of that child’s rights, and thereby, render the intervention unethical. As Boyden & Ennew state: “It is not ethical to expose a child (or an adult) already vulnerable to any additional risk through an investigation that carries no benefit for the child” (1997,

p. 43, in Clacherty & Associates, 2001). This research programme had to be an ethical intervention for the vulnerable children living in the partnering communities.

1.3.3. Defining Community:

Community is a difficult concept to define. The definition of community as constituted largely within defined geographical boundaries was not necessarily applicable in this research context. Rather, community was defined as a relational interaction of social ties that draw people together (Heller, 1989, in Duffy & Wong, 2000), often in combination with a sense of collective political power (Duffy & Wong, 2000). Sarason (1974) defines community as “the perception of similarity to others, an acknowledged interdependence with others, a willingness to maintain this interdependence by giving to or doing for others what one can expect from them, the feeling that one is part of a larger dependable and stable structure” (In Duffy & Wong, 2000, p. 17). Community² is therefore based on the presence of a number of key elements: (i) *Membership* wherein people see themselves as belonging, linked by strong connectedness and interdependence. In the current context, the community could be an element of the secure base that generates a sense of being affiliated with, and part of, a larger whole. (ii) *Influence* is reflected in people’s belief that they can make a difference over what happens in their community. (iii) *Integration* is derived from the traditionally communal nature of African society as well as the African ideological ethic of *Ubuntu* (Mkhize, 2004; Vilakazi, 1991). The concept of *Ubuntu* originates from the *isiZulu* saying, ‘*Umuntu ngumuntu ngabantu*’ - ‘you are a person through others’. (iv) *Emotional connection* is generated from a shared history, time, place and experience that creates social, emotional and cognitive attachments, which motivates community participation (Unger & Wandersman, 1985, in Duffy and Wong, 2000).

On the basis of these characteristics, the community is the obvious and correct source from whom vulnerable children can gain a sense of belonging and connectedness. One aspect of this research programme examined community conceptualisations of “community” to see if grass-roots definitions concur with the above-mentioned literature based definitions.

1.3.4. Rationale for the focus on strengthening the community to support vulnerable children:

In western countries, vulnerable children have become the domain of child and social welfare organisations. Africa’s much-overstretched child welfare societies are caught between two worlds of operation: first world models of one-to-one focus on permanency planning and intervention for vulnerable children; and third world models in which the focus shifts to community development. In South Africa, before the first democratic elections, the core of the child welfare business was on needy children amongst the 5 million ‘white’ residents (Guest, 2001). Even then the limited personnel and financial resources left many social workers overburdened with excessive caseloads.

² Kelly, Ntlabati, Oyosi, van der Riet & Parker (2002, p. 4) use the term ‘community’ to refer to the contextually-based set of structures and practices that determine relationships between people who share common beliefs, attitudes and aspirations. The term ‘social’ refers to the broader context of society as a whole in which the structures and operations have an influence on the opportunities and aspirations of individuals and communities.

Since 1994, the plight of all children has been included in service delivery endeavours. The challenges facing social welfare organisations have been enormous. The political process of transformation have created enormous stress for social workers and the population they serve (Guest, 2001).

By the late 1980's and early 1990's, the impact of the AIDS pandemic was barely an issue of concern for South Africa where its full impact had yet to be realised (van Dyk, 2001). The concern, with respect to vulnerable children had been primarily on the plight of abandoned and orphaned children (McKerrow, 1995). In KwaZulu-Natal, decades of political violence had left many bereaved and destitute children (Guest, 2001), disintegrated families and fragmented communities (Desjarlais, Eisenberg, Good & Kleinman, 1995; Higson-Smith & Killian, 2000). The old first world models of intervention were no longer applicable. There was a shift towards community-based models of intervention. The sheer magnitude of the AIDS pandemic added impetus towards empowerment models that both encourage and enable communities to care for their vulnerable children. This had the added advantage of heeding the lessons learnt in first world contexts to keep children out of costly orphanages (Guest, 2001; UNICEF, 1999).

Furthermore, debates have raged within Africa about the relevance and appropriateness of conventional mental health and social service models of intervention (Nell, 1990; Bieshevel, 1991). Clearly there is a vast cultural divide between western concepts and cultural ideas about the ways in which people, including children, respond to extreme psychosocial pressures and distress (Swartz, 1998). Although psychology, as a discipline, may have played a role in perpetuating racism through its lack of advocacy and action (Durrheim & Mokeki, 1997), it can also take credit for the realisation that an understanding and engagement with the psychology of oppression (Nicholas, 1993) was necessary in order to develop meaningful relationships across cultural divides.

Traditionally, many African societies have been considered to be largely communal in nature since the strong extended family system is firmly rooted within communal and tribal structures. Culture can be considered to be a basic way of life, an attitude to life, others, work and business. These attitudes are known to differ in some substantial ways between African and western people (Boon, 1996). Boon (1996) believes that the differences are so basic that they impact on the ways in which people communicate and on their actions, and as such should be regarded as of critical importance in any intervention. Exemplifying this point, in his discussion about cultural models of mourning, Bopape (1995, p. 226) concluded that "it is important for the helping professions to take into account the socio-cultural factors in giving assistance to the bereaved."

It seems imperative that social scientists, if they are to take their aim of participation seriously, must understand indigenous resources, relationships, helping and problem-solving networks (Osei-Hwedie, 1993). The ideologies that underlie local ideas, theories, rationale, philosophies and values (Osei-Hwedie, 1993) need to be taken into consideration when developing intervention strategies.

There is a need for culturally sensitive models that are informed by Afrocentric philosophies (Avilia and Combs, 1985).

There are several ways in which the principles of empowerment and of *Ubuntu* have been systematically considered in this research programme:

- Adoption of participatory action research methodology ensured co-operation, emphasised collective action, and provided forums for participation and dialogue so that team work could be promoted (Bhana, 2002). There was a specific goal to create meaningful networks and cultivate collaboration both within and between communities.
- There was a strong reliance on group commitment, responsibility and decision making. Whilst respecting individual input, the collective action and decision making led to much variation between the partnering communities in terms of the way in which they offered psychosocial support to their vulnerable children.
- Efforts were made to resolve conflict that emerged within groups in order to promote unity and cohesion.
- There was recognition of the fact that each person's background was integral to who they are and what they have to offer (Oakly-Smith, 1991; Tutu, 2002).
- The use of starting and closing rituals served to reinforce group membership.

Participatory action research therefore became the research ethic for the evaluation of the programme. Whilst conducting the programme, the concept of *Ubuntu* was foremost in the mind of the researcher in order to optimally use all opportunities to build group cohesion and reinforce the underlying philosophy that guided this grass-roots programme.

Chapter 2

The HIV/AIDS Pandemic and its Impact on Children

“Neither words nor statistics can adequately capture the human tragedy of children grieving for dying or dead parents, stigmatised through their association with HIV/AIDS, plunged into economic crisis and insecurity by their parents’ death and struggling without services or support systems in impoverished communities”
(UNICEF, 1999, p. 3).

Over the course of history, humankind has frequently faced the challenge of coping with various forms of natural, man-inflicted and disease-related disasters. Societies have always had individuals who are living in particularly disadvantageous circumstances: for example, society has needed to cope with children who are orphaned or whose parents are unable to support them. However, the sheer scale of the HIV/AIDS pandemic and the number of affected children appears to be unprecedented in history (Hunter & Williamson, 2000; Sherr, 1995). International aid organisations have repeatedly demonstrated major concern for the people and communities who have suffered the ravages of war and political violence. In 1998, there were 200,000 deaths as a result of conflict and war, whereas AIDS killed 2.2 million people (UNICEF, 1999). The AIDS pandemic can rightly be called the world’s most deadly undeclared war, with Africa bearing the brunt of its pernicious impact (UNICEF, 1999). Over 85% of the world’s HIV infected people live in Africa, where AIDS is the leading cause of death (Gow, Desmond & Ewing, 2002).

However, the major tragedy does not lie in the number of infections and deaths, but in the vast numbers of children adversely affected by HIV/AIDS. Those who are dying from AIDS are primarily young adults who are in their childbearing years (Shisana & Simbayi, 2002). Large numbers of children are themselves HIV+ with many children either ill or dying from the disease (Hunter & Williamson, 2002). The impact of the pandemic on the physical and psychosocial well being of children has been particularly devastating. The suffering of children in communities where the disease is prevalent is cumulative in nature as they witness their parent’s illness, are orphaned, experience numerous losses, whilst living in communities already weakened by underdevelopment, poverty (UNICEF, 1999), and decades of political strife. In terms of its human and social ramifications, there can be no doubt that AIDS constitutes a global crisis of immense proportions. By 2011, 56% of households in South Africa will have at least one HIV+ person or someone who has died of AIDS (Giese, 2002). The responsibility of caring for the destitute, sick and dying will impact on 46% of uninfected households.

2.1. The demography of a modern day plague:

“The HIV/AIDS pandemic is a continuously evolving, progressive disaster” (Foster & Williamson, 2000, p. 277). Statistical projections and estimates cannot be regarded as entirely reliable or valid. The problems of definitions across cultural and language groups, diverse methodologies, respondent motivational variables and migratory patterns all contribute to the miscellany which exists in estimating the scale of the problem. However, the estimates give credence to the extraordinary human catastrophe that is being faced. It is therefore necessary to begin any consideration about

intervention programmes with an overview of the demographics since these serve to both enlighten and guide one in devising appropriate strategies of intervention. The collaborative research endeavour by the United States Agency for International Development (UNAID), the United Nations Children's Fund (UNICEF) and the Joint United Nations Program on HIV/AIDS (UNAIDS) provides the broadest and most comprehensive statistics on the historical, current and projected numbers of children orphaned by HIV/AIDS³ (Hunter & Williamson, 2002) and thus will be used as the major source of demographic information⁴.

In sub-Saharan Africa, the number of orphans is increasing dramatically both in real and relative terms. By the end of 2001, it was estimated that there were 34 million children who had lost one or both of their parents to AIDS (Hunter & Williamson, 2002), with an expected increase to 42 million orphans in the sub-Saharan region by 2010 - about one third of these orphans will be AIDS-related (ibid.). Worldwide the total number of orphans is predicted to reach 106 million by the year 2010 and more than a quarter of these (25 million) will be HIV/AIDS orphans⁵ (ibid.). In 2001, the number of orphans in Asia (65.5 million) was nearly double those in sub-Saharan Africa (34 million) - the high number in absolute terms reflects the high population density in countries like India, where the seroprevalence rate is 1% amongst the adult population. The inter-country comparisons are interesting, as even in sub-Saharan Africa in 2001, 70% of all orphans were to be found in just 12 countries (ibid.). South Africa has the highest number of actual orphans, followed by India (ibid.).

Before the AIDS pandemic, approximately 2% of children in developing countries were orphans, with about a third of these children being under the age of 5 years (UNAIDS, 2001). In 2001, the number of HIV/AIDS orphans in sub-Saharan Africa constituted 12.4% to 15% of all orphans (UNICEF and UNAIDS figures respectively), with a predicted increase to 24% by 2010. In South Africa, 16% of all children are orphans, of whom more than 70% are HIV/AIDS orphans (Hunter & Williamson, 2002). The 1997 projections for the percentage of all children who would be orphans by 2000, was 25% for Rwanda, Zimbabwe, Zambia, Malawi, Tanzania, Botswana and Burkina Faso (HTS, 1997), with these estimates having been made before the full onslaught of drought and political upheaval in such countries as Zimbabwe and Rwanda.

When statistical estimates are conducted for the purpose of future planning, it is essential to include children living with HIV+ parent/s. In some regions, one in four children born to healthy women will have at least one parent who is HIV+ by the time the child reaches his or her fifth birthday (Palloni & Lee, 1992). No estimates of a similar nature could be found for sub-Saharan countries, but in

³ Note that these international agencies define orphans as children under the age of 15 years

⁴ There is a proliferation of statistical estimates and projections, many of which appear to be highly contradictory. An analysis of the validity of the statistics, which are frequently based on estimates and projections is considered to be beyond the scope of this thesis.

⁵ In calculating the number of orphans there has been a stronger focus on maternal orphans, as the mothers tend to be more readily identifiable. The impact on children of maternal death is more likely to be associated with loss of primary caregivers and nurturers, whereas paternal death is more likely to have socio-economic effects (World Bank, 1997).

Thailand for every maternally AIDS orphaned child, there are twelve children living with an HIV+ mother (Brown & Sittitrai, 1997, in Foster & Williamson, 2000) and for every Brazilian AIDS orphaned child, there are three children living with a mother suffering with AIDS and twelve children whose mothers are HIV+ (UNAIDS, 1997, in Foster & Williamson, 2000).

In order to locate the reader to the province of KwaZulu-Natal in South Africa where this study was conducted, it has been found that this, the most densely populated province in South Africa, is no longer showing population increases (Simon-Meyer, 2000). The number of adults aged 20 to 35 years is expected to decrease by 40% over the next twenty years, but 70% of the children will survive (ibid.). By 2004, there will be an expected 450,000 orphaned children in KwaZulu-Natal and by 2010 this figure will have jumped to 700,000. If half of these children qualify for social grants, the estimated increase in foster grants alone will be R1,4 billion by 2010 (ibid.). The significantly reduced adult caregiver population means that a significant number of children will be raised without the love, care and support of their families.

2.2. Epidemiological factors impacting on the psychosocial well-being of children:

Many epidemiological factors will directly or indirectly change the form of society into which children will be socialised. These factors give insight into the ways in which society will be influencing and changing the socialisation and general status of children living within high prevalence communities and countries. These circumstances need to be considered before suggesting guidelines within which to plan intervention strategies.

2.2.1. The changing face of society:

The HIV/AIDS pandemic has significant implications for population demographics, suggesting that children will be raised in a society that will be different from the one in which their parents were raised. The changing demography indicates the nature and scale of the problem and suggests important shifts in attitudes that are likely to be held by parents, educators and society at large (Giese, Meintjes, Croke, & Chamberlain, 2003; Kolisang & Lourens, 2002; Cook, 1998).

- **Total population loss:** Within sub-Saharan Africa, death rates may double or even triple (UNAIDS, 2001). In a world that can barely sustain its' current population, one needs to acknowledge that death is nearly always emotionally distressing, most especially, if the death results in orphanhood. The social costs of the increased number of deaths are enormous and include disintegration of the family and extended family systems, disruption to all social structures and the pervasive effects of anxiety, grief and fear. As an elderly community stalwart, Mrs Ngubu⁶ said "we are so tired of deaths, we can't even find the energy to cry, to sing, to do all the things that we are supposed to do ... there are just too many deaths every month. Every weekend we spend our time going from funeral to funeral. We are tired" (Personal communication with members of the partnering communities, 2002).

⁶ Pseudonyms will be used throughout this dissertation to protect the identity of community members

- **Life expectancy patterns:** There is an anticipated drop in life expectancy from 60 - 70 years to 40 years or less in nine sub-Saharan countries by the year 2010 (USAID, 1997). Lowered life expectancy detrimentally impacts on one's life plans and the value that one places on the future. Approximately 50% of HIV+ people are infected before their 25th birthday and most will die before their 35th birthday, leaving behind a generation of children raised by grandparents and extended family members (UNAIDS, 2001).
- **Infant and child mortality rates:** HIV/AIDS has a profound effect on the mortality of infants (under 1 year of age) and children less than 5 years of age as a result of MTCT through intrauterine and perinatal infection. AIDS-related mortality will eliminate the gains made in child survival over the past 20 years. Child mortality rates are expected to triple in Zambia and Zimbabwe and double in Kenya and Uganda (South Africa was not included in this study) (ibid.). This could adversely impact on the attachment relationship formed between an infant and the primary caregiver, who will be fearful of the child's chances of survival. One South African report has indicated that HIV/AIDS orphans are 2,5 to 3,5 times more likely to die than non-orphans (HIV Infant Care Programme, 2000, in Giese, 2002).

One of the debates pertaining to treatment and prevention programmes revolves around the issue of providing anti-retroviral treatment (ART) to HIV+ pregnant women. Long-course ART programmes offered during pregnancy in combination with caesarean section deliveries can reduce MTCT to very low rates (Gow et al., 2002). In resource-limited environments, a brief course of ART given to the mother prior to giving birth by caesarean, followed by a short course to the babies after birth, can reduce MTCT by 35 - 50% (Gow et al., 2002). A ten year longitudinal study on 3,004 children showed unequivocally that maternal HIV status and survival are strong predictors of child survival (Nakiyingi, Whitworth, Ruberantwari, Busingye, Mbulaiteye & Zaba, 2002). The risk of child mortality was three times as high for children of HIV+ mothers, with 14% of child mortality being directly attributable to maternal HIV+ status (ibid.). Children whose HIV+ mothers had already died were five times more likely to die before age 5 years, than the children of surviving HIV+ mothers (ibid.). Analysis of these figures can leave no doubt that children are better off physically (and emotionally) if their mothers are able to be the primary caregivers. Withholding ART regimens seems short-sighted and unethical.

- **Age demographics:** In sub-Saharan Africa, there will be 12 times as many children under age 15 as adults over age 64 (McDevit, 1996), leaving a predominantly child population with relatively scarce numbers of adults and elderly people. This will inevitably change concepts of childhood and the needs, responsibilities and rights of children, as well as attitudes towards the elderly. At present, 60% of all people living in South Africa who are classified as poor are either over the age of 60 years or younger than 18 years of age (Woolard & Barberton, in Richter, 2003).
- **Gender ratios:** In South Africa, women have a higher rate of HIV infection (12,8%) than men (9,5%), Within the 15 - 24 age range, double the number of women (12%) were infected than men (6%) (Shisana & Simbayi, 2002). It is probable that there could be 1.5 men for

every woman in some sub-Saharan African countries within the next 20 years (Hunter & Williamson, 2000). It also seems that physiologically immature and post-menopausal women are at increased risk of infection (Adar & Stevens, 2000; Rooth & Dryer, 2002). Within cultural groups who retain division of labour along gender lines, especially in terms of child care being perceived as a gender-specific task, these demographics will significantly impact on general well being of families and communities (Baylies & Bujira, 2002; de la Harpe, de la Harpe, Leitch, & Derwent, 1998; Foster & Williamson, 2000; Marcus, 2002). In addition, this will create a situation in which there are fewer economically active females, even though women will continue to be the backbone and strength behind most community based and public health initiatives (Baylies & Bujira, 2002).

- **Degenerating circumstances of the elderly:** In general older people will suffer more economic setbacks due to the loss of support from their children who die from HIV/AIDS, combined with the perceived obligation that they have to care for orphaned grandchildren. The responsibility of caring for children and the sick will probably fall largely on elderly women, who will also experience a drastic deterioration in their social and material resources for coping (Ayieko, 2003; Hunter & Williamson, 2000).
- **Household composition and co-residence:** The highest prevalence rate (28%) of HIV infection in South Africa occurs in the 25 - 29 age group, followed by the 30 - 34 age group where 24% of HIV+ individuals occur (Shisana & Simbayi, 2002). Thus 52% of HIV+ individuals are within the childbearing, economically-active segment of the population. The consequences are that, firstly, the proportion of households with three resident generations will decrease, as young and middle-aged parents die and grandparents are left with young children in their care (Hunter & Williamson, 1999). The number of households in sub-Saharan Africa that currently have orphans in their care (usually in informal foster placements) is already a substantial proportion of the total. This pattern will increase exponentially in all high prevalence communities, impacting on most families whether they have an HIV+ member or not. Secondly, 16 % of all households may be headed by single parents (Hunter & Williamson, 2000). Even though there is a higher rate of HIV infection amongst women, it is likely that the majority of single parents will be widows (Ibid.). Widows are more likely to be migratory as they seek employment or remarry, while continuing to care for their children (Foster & Williamson, 2000). Furthermore, the extended family, the foundation stone of much of traditional black culture, will be burdened and may collapse under the strain (Foster, 1998; Giese et al., 2003; Marcus, 2002).
- **Geographic Profiles:** Despite concern for the deep rural areas of Africa, people living in the urban informal settlements appear to be at greatest risk of HIV infection, followed by those resident in urban areas (Shisana & Simbayi, 2002). The drift towards urbanisation for economic survival has given rise to many informal settlements that lack basic facilities and present their own risk of opportunistic infections. In the main, informal settlements are poverty stricken ghettos. Nevertheless, trends towards urbanisation continue to increase in most developing countries. There is however a tendency for urban dwellers to return to rural areas when they become ill and unemployable in the towns and cities (Foster & Williamson,

2000; UNICEF, 1999). In addition, the townships of South Africa carry a legacy from the *apartheid* era and may lack infrastructure, similar in many respects to the informal settlements found elsewhere in the world.

2.2.2. Transmission of HIV:

In 2001, there were 36 million HIV infections in sub-Saharan Africa. This constitutes 72% of the approximately 40 million HIV+ people in the world (Hunter & Williamson, 2002). There were 4,5 million HIV+ people in South Africa, constituting 11.4% of the total population (Shisana & Simbayi, 2002). Many children are HIV+ (Shisana & Simbayi, 2002; UNICEF, 1999; WHO, 2003), either through MTCT, sexual abuse, or human-to-human blood contact.

The medical facts about HIV are beyond the scope of this dissertation, however the modes of HIV transmission have a particularly adverse impact on children. HIV is transmitted sexually, from mother-to-child and through human-to-human blood contact.

(1) **Sexual transmission** of HIV has many direct implications for children:

- If one parent is HIV+, the probability of the other parent also being HIV+ is high, meaning that a child could lose both parents within a relatively short period of time (UNICEF, 1999; Wild, 2001). Siblings may have acquired HIV peri-natally through MTCT. Intrafamilial family mortality rates are very high.
- Since the virus is predominantly sexually transmitted, the disclosure of a HIV+ diagnosis can lead to major conflict. The South African study by van Dyk and van Dyk (2003) found that violence, marital breakdown, neglect and being disowned are among the consequences of women disclosing HIV+ status to their sexual partners. The stigma is too much for many individuals. There are also pervasive beliefs that people who die from an AIDS-related death bring shame to their families and communities as a result of which they suffer a “bad death” (Marcus, 2002). Their families bear the brunt of stigmatisation and discrimination long after their deaths (Mallman, 2002).
- Child sexual abuse rates are likely to increase as a result of some of the myths that have developed about HIV treatment. For example, there is a myth that ‘having sexual intercourse with a virgin cures HIV’. This has given licence to some perpetrators of child sexual abuse and individuals desperate to seek a cure for their own HIV+ status, to sexually abuse and rape young girls - presumed to be virgins. A disproportionate number of children who were raped were found to be HIV+ (McKerrow, 1997). This myth has enjoyed much media and grass roots attention and has probably increased the risk of children being sexually abused and infected by an HIV+ individual. The emotional and behavioural consequences of child sexual abuse victims has a profound impact on many aspects of a child's functioning (Killian & Brakarsh, 2004). In addition, sexual abuse exposes children to severe discrimination and hardship. For example, Kriel (2001) found that many educators inaccurately hold the belief that once a girl child has been sexually abused, she will entice and provoke boy children into sexual activity.

- In communities in which there are high rates of gender-based violence, adolescent girls are being infected at rates five or six times higher than boys (UNAIDS, 2001). In addition, in situations of civil disorder and war, young women and girls are systematically targeted for sexual abuse (Adar & Stevens, 2000; UNAIDS, 2001).

- (2) **Mother-to-child-transmission (MTCT)** accounts for about 90% of HIV+ children under the age of 15 years (UNAIDS, 2001). Over 105,000 babies in South Africa were born HIV+ in 2000, of whom about 60% were not expected to live beyond 5 years of age (Department of Health, 2000, cited in Giese, 2002). HIV can be transmitted to an infant during pregnancy, labour and delivery, or breastfeeding (UNAIDS, 2001). It seems that 15 - 30% of infants born to HIV+ mothers will be infected if they are not breastfed and that breastfeeding increases the risk of MTCT by 10 - 15% (UNAIDS, 2001).

Significantly the western world has almost eliminated MTCT through the use of VCT, access to antiretroviral therapy, use of long-term regimens of MTCT prevention programmes, safe delivery practices (including elective caesarian sections) and the widespread use of infant feeding formulas (UNAIDS, 2001). Effective and feasible interventions to reduce MTCT are available and could save the lives of 300,000 children each year and half the risk of infant infection (ibid.). A cost-effective modality of intervention involves short term use of prophylactic antiretroviral therapy combined with nutritional formula feeding (Ibid.).

- (3) **Human blood-to-blood contact:** Members of the same household are more likely to become infected through the sharing of cutting instruments (e.g. razors) or through cleaning bleeding or suppurating wounds when the caregiver also has an open wound. However, there is still limited awareness of the need to use latex gloves to prevent HIV infection. In poor households, people share toothbrushes (Personal communications, 2002) and since bleeding mouth sores often accompany oral thrush, toothbrush-sharing may also create opportunities for human blood-to-blood transmission as well as bacterial infections.
- (4) Since HIV lowers the functioning of the **immune system**, opportunistic viral and bacterial infections can spread rapidly through a family or co-habiting groups of people. Children are particularly prone to pneumonia, TB, persistent diarrhoea, growth failure, swollen lymph nodes, chronic cough and fever (Giese et al., 2003). The lack of basic hygiene and sanitation created by lack of access to running water in many South African homes and schools exacerbates the spread of these opportunistic infections (McKerrow, 1997; Statistics South Africa, 2000).

The proliferation of various myths about the mode of HIV transmission has diminished the impact of information dissemination programmes. For example, many community members believe that the mode of transmission has been deliberately distorted in western medical circles to bring shame and embarrassment to African people - the primary sufferers of this pandemic. For instance, a frequently

quoted adaptation of the AIDS acronym, "Africa Is Dying Slowly" suggests that HIV is a racially-inspired viral disease spread through contaminated water with the express purpose of killing off black people, whilst bringing shame by suggesting that the high mortality rates are due to their immorality (Personal communication, 2002). Although there has been an increase in knowledge about HIV/AIDS, there is no doubt that high levels of distrust, lack of education that would enable people to accurately interpret prevention messages, and high illiteracy rates have enabled myths to abound in many communities. The South African government's stance on HIV/AIDS has further contributed to the disinformation about the nature and impact of this disease. The government policies have sown seeds of confusion and distrust, instead of united action and clear policies.

2.2.3. Course of HIV/AIDS:

The protracted incubation period of about ten years from the time of HIV infection to death from AIDS (Hunter & Williamson, 2002) means that being orphaned is only one of the ways in which children are adversely affected by AIDS. The clinical course of HIV is unpredictable, involving intermittent crises followed by periods of relatively good health (Flemming, 1994; van Dyk, 1999; UNAIDS, 1999; Wild, 2001). Therefore, it is probable that the children of HIV+ parents will face many adjustments and major life stressors as they journey through life. The estimated ten-year span between infection and death has broader implications at the epidemiological level:

- Even in countries in which the seroprevalence rates have declined, the number of orphans will continue to remain high for at least a further decade (UNICEF, 2001). Uganda's statistics demonstrate that the rate of infection was around 14% in the late 1980's (Hunter & Williamson, 2002) and although the rate of infection had decreased to only 5% by 2001, the number of orphans increased throughout the 1990's, with the decline in the number of new orphans only just beginning at the turn of the century (Hunter & Williamson, 2002).
- Likewise, should a vaccine be discovered, a whole generation of children are still likely to suffer immense hardship, as those already infected become sick and eventually die. Moreover, the costs of vaccines may create service delivery difficulties as is currently being witnessed in South Africa where the Department of Health is still deliberating about their roll-out of ART treatment regimens after having been ordered by the High Court to provide such treatment. In fact, even if successful vaccines were to be discovered, mortality rates would only stabilise 15 to 20 years later.
- Even if effective prevention programmes were implemented, the unusually long HIV incubation period means that mortality rates would begin to plateau in about 2020 (UNAIDS, 2001). Prevention in itself is a long term process since the most beneficial prevention programmes aim to change behaviour by targeting attitudes, beliefs and sexual practices, as well as through information dissemination.

It is evident that the long incubation period of HIV/AIDS makes this a particularly debilitating plague for children living in high prevalence communities. Nevertheless, one of the best ways of assisting orphans is to prolong the life of their parents (Fox, 2001; Fox et al., 2002; Giese et al., 2003). The above-mentioned epidemiological factors will be experienced at the societal level,

however, the repercussions for families and individuals are the ones that will more directly impact on the well-being of children.

2.3. General issues impacting on the well being of children

Despite the grim statistics, not much is known about how children, families and communities are actually responding to and coping with the pandemic (Foster, 1998; Wild, 2001). Even less has been written about how to address the emotional and social needs of children directly affected by this type of loss (Germann & Madörin, 2002; Giese et al., 2003). However, there appear to be three major variables that underscore the other more specific and individualised impact areas. Nearly all children living in high HIV/AIDS prevalence communities live in appalling poverty, experience disrupted education and are the target of discrimination and stigmatisation. The interaction between these three fundamental areas of impact creates the major chronic stressors that place children at incrementally increased psychosocial risk. Discrimination, for example, emanates from poverty, lack of education and association with HIV/AIDS. The focus in the following subsection will be on outlining these general issues, before looking more specifically at the psychosocial impacts on the individual child and family.

2.3.1. HIV/AIDS and poverty:

There is no doubt that HIV/AIDS is a poverty-related illness (Hunter & Williamson, 2002; UNICEF, 2001; Gow et al., 2002; Foster & Williamson, 2000). HIV/AIDS is most likely to spread rampantly in poverty-stricken communities, both in third world countries as well as in first world contexts, such as in the United States of America (Geballe & Gruendal, 1998; Giese et al., 2003; Taylor et al., 1999). The high risk situations for rapid spread of HIV have repeatedly been found to be impoverished, disempowered communities, who have undergone rapid urbanisation, with the new-found anonymity of town and city life, combined with the social upheaval and disruption associated with political violence, war and counter-insurgencies (Hunter & Williamson, 2002; Marks, 2001; Zwi & Cabral, 1991). South Africa and other sub-Saharan countries rank high on this risk scale (Barbarin, 1999; Dorrington, 1999; Gow et al., 2002; Johnson & Dorrington, 2001; Marks, 2001).

The socio-economic impact of HIV/AIDS will vary across families, communities, provinces and countries, but statistics indicate the following impact areas:

- **Income decline:** The GDP will show a slow but steady decline (UNICEF, 2000), negatively impacting on all aspects of life. The greatest impact will be felt at the micro and meso systemic levels - families, communities and micro businesses will substantially suffer (Foster & Williamson, 2000). Households are likely to experience an income decrease of 45 to 52% (Hunter & Williamson, 2000), while expenses related to health care are quadrupled (UNICEF, 2000)⁷. Many people suffering with AIDS-related infections spend their limited resources seeking cures for their sickness, thereby leaving family finances severely depleted in even relatively wealthy sectors of the population (Ntozi & Mukiza-Gapere, 1995). The

⁷UNICEF (2000) estimated a decrease in real income terms of 52 - 67%. This figure also takes into account the increased health care expenditure.

curtailment of much needed income is most likely to occur as families endeavour to carry the financial burden of illness, hospitalisation, treatment regimens and then, the care of orphans and extended family members (Foster & Williamson, 2000; Marcus, 2002). Frequently the family's resources will be depleted, leaving no contribution towards future care, or inheritance, for the children (McKerrow, 1995; UNICEF, 1999; Wild, 2001).

- **Costs of illness, death and funeral:** When a breadwinner is ill, the family income shrinks and at the same time the costs related to traditional and clinical treatment soar (Fox et al., 2002). Funeral costs are a drain on resources, as expensive funerals are expected by the communities. In rural and even most peri-urban areas, individuals are buried in the land surrounding the household. Children often see their families' graves on a daily basis.
- **Fewer economically active adults:** The number of economically-active individuals will decrease and there will be a corresponding increase in dependent sick adults, children and young people who will need to leave school early and enter the labour force (USAID & the Synergy Project of TVT Associates, 2001; UNAIDS, 2001; UNICEF, 1999). This will exacerbate the already unacceptable South Africa statistics of 35% of rural African children between the ages of 6 and 17 years, do not attend school (Johnson & Dorrington, 2001) and it is particularly girl children who are likely to be discriminated against in this regard (Global Movement for Children, 2003).
- **Child labour,** both within and outside of the home, will become more widespread despite an increasing awareness of children's rights (Cook, 1998; COPE, 2002; Cluver, 2003; Mallman, 2002; Muchiru, 1998). In twenty sub-Saharan African countries, children aged 5 -14 years who had been orphaned were less likely to be in school and more likely to be working in excess of a 40-hour week (Hunter & Williamson, 2002). For example, in a Kenyan sample, 52% of orphaned children were not in school, while only 2% of non-orphaned children were out of school (ibid.). Many children will drift to the streets.

Globally an estimated 250 million children (aged 5 - 14 years) from developing countries are working, of whom 60 million are exploited in the worst forms of child labour (Global Movement for Children, 2003). Some 120 million children work in excess of 9 hours per day and 80% of these are not paid for their labour. A further one million children every year enter the multi-billion dollar commercial sex trade, where they are coerced, bonded by debt, sold or simply kidnapped (ibid.). These horrific trends are likely to escalate due to the dire poverty in which many children live. Child labour is not only the result of poverty. It simultaneously perpetuates poverty and repeats the cycles of disadvantage in the long run.

- **Business, commercial and agricultural impact:** All aspects of income generation are adversely affected (Cook, 1998; UNICEF, 1999). Labour costs skyrocket as economically-active adults fall sick; rates of absenteeism increase; productivity declines; costs for recruitment and retraining are incurred; and there is increased demand for the provision of insurance and health resources. The cumulative impact of these factors may cripple many

businesses, industries and agricultural enterprises (Hunter & Williamson, 2000). Some local government departments now only permit employees to hold collective weekly memorial services for recently deceased colleagues, during lunch breaks, as the mourning rituals and memorial services were negatively impacting on the number of productive working hours (Personal communication, 2001).

Subsistence farming has traditionally fed families and communities. The decrease in agricultural activity has led to (i) correspondingly compromised nutritional status and widespread malnutrition (Care International Zambia and Family Health Trust and Family Health International; 2001); (ii) loss of inter-generational transmission of skills and knowledge; and (iii) inability to follow prescribed cultural mourning rituals that require the slaying of an animal since, at times, there are no animals available to be slaughtered. Food consumption in sub-Saharan Africa has been estimated to have dropped by 41% over the last decade (Hunter & Williamson, 2002). Malnutrition and stunted growth rates have increased (Giese, 2002) and many children are no longer being trained in healthy eating or food preparation by their primary caregivers.

- **Costs of social and health services** will be stretched beyond capacity, creating a financial drain, saturation of available resources and demotivated staff who feel over-whelmed and over-burdened (Gow et al., 2002). In addition because of the disheartening nature of their jobs, it has been noted that there has been a drift away from social and welfare careers, leaving a high probability that these services will become even more understaffed (Hunter & Williamson, 2000; UNICEF, 1999). Most sick people will need to be given home-based care placing extra financial and psychological stress on the families. National budgets are adversely affected as health costs soar, leaving substantially less for education, welfare, development of infrastructure and other government services.

Basic human rights necessitate that all people have their most basic needs for food, shelter, clean water, clothing and health care met. The fact that there is no food security for the majority of Africa's residents augurs poorly for the future. Tenuous access to food on a daily basis leads to malnutrition, illness-proneness, risk of mental retardation, inability to concentrate at school due to hunger pangs, as well as a host of social problems. Compromised health care precipitates additional health problems: people are not immunised; they become more illness-prone; they have no access to contraceptive, bacterial and viral infection control measures; and they lack understanding of preventive and treatment programmes. The deficient infrastructure means that increasingly people will not have access to clean water, sanitation, adequate housing, or ventilation. The unavailability of public transport facilities force people to walk long distances to school and health facilities, so that they are tired on arrival or give up *en route*. Over-crowding leads to increased irritability, loss of privacy, increased stress and daily hassles.

The HIV/AIDS pandemic has reversed much of the development work that has been conducted in sub-Saharan African countries to offset colonial adversities (Gregson, Garnett & Anderson, 1994; UNAIDS, 2001). These nations are becoming poorer (World Bank, 1997). The sheer magnitude of the pandemic dictates that all social service agencies need to combine and co-ordinate intervention strategies for the sake of future generations. It is time for the government, NGO, CBO, FBO sectors, as well as civil society to unite and work synergistically.

The socio-economic factors are not presented to paint a picture of gloom and doom but to inform the type of intervention strategies that are needed. The multi-directional and circular impact of these factors clearly indicate that any meaningful intervention has to be aimed at large scale, cost effective, readily replicable intervention strategies at national, community, family and child levels. African people have historically and still do, live in relatively small but cohesive communities (Ayieko, 2003; Giese et al., 2003). These strong interdependent microsystems can be powerful. However, in the face of the current pandemic, they need support to counteract the negative impact of HIV/AIDS on children (Foster, 2001). There is the potential to strengthen communities, capacity build and network to create co-operation between service organisations and communities (Phiri et al., 2000). However, it is unlikely that any intervention strategy can have a long-term impact in the absence of concerted poverty alleviation and community development programmes.

2.3.2. Disrupted education:

One of societies' major gatekeepers is education. People are able to move up or down the socio-economic ladder through educational qualifications. However, schools within poverty-stricken communities are renowned for their high failure rates, demotivated staff, scarcity of educational equipment and lack of resources, uninvolved parents who cannot provide assistance with homework and no resources for extracurricular activities (Shaffer, 2002). The major factors contributing towards educational difficulties are socio-economic in nature.

In addition to the socio-economic variables, educational problems are more evident in vulnerable children thereby dooming their future prospects for adequate adjustment and development (Giese et al., 2003; Hunter & Williamson, 2002; Smart, 2000). In households that are affected by AIDS, children's school attendance and performance tends to decline and they are deprived of the healthy social interaction that is an essential ingredient of psychosocial well-being (Cluver, 2003; UNICEF, 2002). There are several factors associated with the HIV/AIDS pandemic that negatively impact on children's educational opportunities and advancement. These are likely to manifest in terms of scholastic progress and achievement:

- **Sensitivity to emotional distress in primary caregiver:** Children are usually sensitive to the emotional state of their primary caregivers (Rutter, 1990). When primary caregivers become stressed, distracted or ill, the child is likely to become anxious and concerned. HIV+ individuals seem to have insight into the psychological issues involved in this diagnosis as

many ask for assistance with personal issues and report concomitant psychosocial distress (du Plessis, Bor, Slack, Swash & Colbelt, 1995). Manifestations of this distress in adults can take the form of impairment in daily functioning (Sanford, Offord, Boyle, Peace & Racine, 1992) or the development of significant symptoms, warranting a diagnosis of one or more forms of psychopathology in children. The symptomatology may take the form of (i) internalising disorders such as anxiety, withdrawal, rumination, social isolation, depression, survivor-guilt and low self esteem; (ii) externalising disorders: for example, oppositional, aggressive, hyperactive or antisocial behaviours; (iii) learning and cognitive difficulties including impairments in intellectual or academic functioning, lack of concentration, distractibility; (iv) substance use disorders; or (v) more severe and pervasive forms of social and emotional psychopathology (Corr, 1996; Lutzke, Ayers, Sandler & Barr, 1997; Kazdin, 2000; Tremblay & Israel, 1998). All forms of emotional distress negatively impact on scholastic functioning. For example, a Ugandan study showed that older children reported a 26% decline in school attendance and 28% decrease in average school performance following orphanhood (Gilborn & Nyonyintono, 2000). In Mozambique, 5% of families reported having withdrawn children from school in order for them to help at home (UNICEF, 2002). Improved scholastic performance and intellectual functioning are accepted as valid indicators of effective therapeutic intervention (Kazdin, 2000).

- **Increased and age-inappropriate responsibilities:** As primary caregivers become pre-occupied, distressed, ill, or are grieving, there are likely to be increases in the responsibilities that the child is expected to shoulder (Geballe et al., 1998; UNICEF, 2000; USAID and the Synergy Project of TVT Associates, 2001). Children may be expected to perform (i) domestic chores such as washing, cleaning, fetching water and wood, and doing laundry; (ii) agricultural tasks such as herding livestock, working the agricultural land and ploughing; (iii) caring for younger children, handicapped or elderly people, including taking responsibility for their physical and emotional safety, changing nappies, washing, cleaning and feeding; (iv) caring for the sick by washing, feeding, medicating, dressing wounds, changing bedpans (about one sixth of patients with AIDS are bladder and bowel incontinent and were being nursed at home (PACSA, 2004); and/or (v) income generating activities, for instance begging, hawking, prostitution, farm and domestic labour (Foster & Williamson, 2000; Giese et al., 2003; Gilborn & Nyonyintono, 2000; Smart, 2000).

Responsibility for performing a set of household chores is beneficial in terms of developing a child's self esteem, competence, self-discipline, skills and sense of being part of a collective who share tasks and commitments (Cook, 1998). However when a child is over-burdened by these responsibilities, some of which may be age-inappropriate, it is detrimental to the child and contrary to his or her basic rights (UNAIDS, 2001). The effect of increased tasks and responsibilities is that the child is taken out of the classroom and away from friends and peers. S/he is excluded from developmentally appropriate and necessary activities such as

playing, sports and other socialisation activities. The child's social support circle decreases and the child begins to feel different and alienated (Cohen, Underwood & Gottlieb, 2000). By force of circumstances, s/he is less likely to develop an internal locus of control - a variable that is recognised to be resilience-promoting⁸ (Masten, 2001). Usually in the absence of discussion with the child, adult family members make the decision that a child must take on extra responsibilities, or drop out of school, in order to take care of sick relatives or younger children (Foster & Williamson, 2000; Gilborn & Nyonyintono, 2000). Girl children are usually targeted for such responsibilities and this in turn negatively impacts on women's status within society (Cluver, 2003; UNAIDS, 2001).

- **Economically-based discrimination:** Families frequently lack the financial resources for continued school attendance, even in countries that have policies that support free and compulsory education. The additional expenses of uniforms, stationery, snacks and excursion costs, in combination with poverty-related discrimination, operate to exclude poor children. School fees have been identified as a major barrier to accessing education (Giese et al., 2003). There were numerous accounts of children and their families being turned away, intimidated or discriminated against at school, held back a year, prevented from writing examinations and withholding of school reports on the basis of non payment of school fees (Personal communication, 2002). Furthermore the policies in some countries significantly contribute to stigmatisation through the practice of having some families pay for schooling, while a remission of fees is offered on the basis of needs-based criteria to poor children. The government subsidies for non-fee paying scholars are minimal, thereby discouraging both principals and fee-paying parents from enrolling pupils on a fee-remission basis. Whilst government policies stringently regulate against discrimination on the basis of fee-payment (School's Act of 1996 of SA), in practice the social and emotional repercussions for children who are admitted on fee-remissions is extremely distressing and discriminatory (Giese et al., 2003; Smart, 2000).
- **Supply and quality of education:** The supply and quality of education will be affected by high absenteeism rates and deaths of educators (Babcock-Walters, Booyens, Desmond, Dorrington, Ewing, Giese, Johnson, Gow, McKerrow, Motala, Smart & Streak, 2002; USAID and the Synergy Project of TVT Associates, 2001), the closing of schools due to decreased enrolments and a reduction in budgets for educational systems due to the increased demand for health services (Shaeffer, 1996). Early childhood education programmes are likely to lack the resources to expand (ibid.). Educators may be reluctant to work in heavily infected areas because they fear infection through contagion (a misconception), or because of the emotional stress created by the deaths of pupils and their family members. The

⁸'Locus of control' refers to an individual's belief in their ability to influence what happens to them and to directly affect the external environment. Perhaps a more suitable term would be 'locus of preferred activity,' which refers to an individual's belief that s/he is able to choose her or his own activities, within culturally defined boundaries (Aldwin, 1994).

financial implications for education budgets will be affected bi-directionally: nationally, less money is likely to be available for education expenses, while simultaneously, more orphans will require fully subsidised education (Giese et al., 2003).

In addition the witnessing of numerous deaths of young people may lead to a change in priorities so that there is less value placed on education. This perception could be coupled with a belief that the available education is of a poor quality and therefore education becomes unworthy of a child and family's investment (Babcock-Walters et al, 2002; USAID and the Synergy Project of TVT Associates, 2001).

There is little doubt that when resources are scarce, it is the orphans who will have to drop out of school (Foster et al., 1997b; Smart, 2000; UNAIDS, 1999). The net result of these factors is that children are likely to forfeit access to the socialisation and gate-keeping functions of schools and become dislocated from their peers. Schools perform numerous functions beyond formal education. Whilst most educators would argue that schools in developing countries fail in their responsibility of offering 'an education for life' (March & Craven, 1998; Shaffer, 2002), school is still an agent of socialisation influenced by the dominant ideology of the country and is a major mechanism through which children are afforded the opportunity to change their status in society. Disrupted education jeopardises the developmental progress of vulnerable children (Foster et al., 1997a; Ntozi, 1997; Smart, 2000). In South Africa, the departments of health and education collaborated to introduce a school-based life-skills programme in 2000, however an evaluation of this programme showed that it was conducted erratically and was rather skeletal in operation (Fox et al., 2002; Kelly, Ntlabati, Oyosi, van der Riet & Parker, 2002).

2.3.3. Stigma, secrecy and social isolation:

There is a great deal of stigma associated with HIV infection because of the widespread belief that HIV only affects bad and immoral people (Clacherty & Associates, 2001; Mallman, 2002; Smart, 2000), who are perceived to be shamefully different (Fox et al., 2002). In fact, society has responded to the plight of HIV+ people with intense prejudice, subjecting them to systemic as well as individualised disadvantage and discrimination. Society's response has forced many people not to reveal their HIV status for fear of prejudice and marginalisation, with the result that many HIV+ people are deprived of the help they would otherwise have received (Smart, 2000). Consequently people living with HIV or AIDS are one of the most vulnerable groups in our society (Strode & Barrett Grant, 2001, p. 9). The pervasive prejudice that is directed against children who are perceived to have the virus or are in any way associated with it, is one the most disheartening phenomenon associated with this pandemic (Clacherty & Associates, 2001).

In the case of HIV/AIDS, stigmatisation manifests in a variety of different ways that revolve around discrimination. Discrimination has been defined in the Constitutional Court of South Africa as

“treating people differently in a way which impairs their fundamental dignity as human beings who are inherently equal in dignity (Prinsloo vs van der Linde and Another 1997 (3) SA 1012 at 1026 F-G, in Strode & Barrett Grant, 2001). Discrimination is dehumanising and illegal, yet widely practised. According to both the Constitution and the Equality Act neither the state nor any person may unfairly discriminate against children and youth. Nevertheless, discrimination takes many forms: overt in the forms of intolerance, hatred and even violence; or more subtle and covert, where an attitude makes a child feel inferior (Global Movement for Children, 2003). Discrimination is unacceptable in that it contradicts the basic principle that all children are born equal in dignity and rights (Fox et al., 2002; Giese et al., 2003).

Moreover HIV+ individuals suffer as a result of the both the attitudes and behaviours of others. By definition, prejudice and stigma are characterised by the holding of derogatory social attitudes or cognitive beliefs, expressing negative affect and displaying hostile or discriminatory behaviour towards members of a group on account of their membership of that group (Brown, 2001, in Strode and Barrett Grant, 2001, p. 3). As Burris (1999, in Strode & Barrett Grant, 2001, p. 3) points out, stigma takes the form of a social relationship between a stigmatised person and another based on the shared belief that some part of the stigmatised person's identity is spoiled and tainted. This creates a situation in which both the stigmatised individual and the other person share a belief that the stigmatised individual has been discredited, disgraced and become unacceptable, rendering them fundamentally and shamefully different. Just as in Biblical times, those suffering with leprosy were ostracised, isolated and driven away from normal social interaction, so too are those affected by HIV/AIDS. Despite the various programmes aimed at information dissemination, ignorance at grass roots levels about the mode of transmission of HIV creates widespread discrimination against HIV/AIDS associated individuals.

In addition, ignorance about the modes of HIV transmission lead people to fear 'catching' it through contact with an infected person or with their belongings (Cook, 1998; Mallman, 2002; Taylor et al., 1999; USAID and the Synergy Project of TVT Associates, 2001). A natural consequence of this ignorance is that even relatively well-educated individuals may refuse to have any association with an HIV+ individual in an endeavour to protect themselves from either contagion or infection. The social support systems (including nuclear and extended family, religious organisations, health and education facilities) of HIV+ individuals and their families dry up very rapidly (Clacherty & Associates, 2001; Cook, 1998). As a result, many prefer to refer to HIV/AIDS with a string of euphemisms (Marcus, 2002, p. 10) rather than refer to it by name. Terms such as *intoyakhe* ("this thing"), *amagama amathatu* ("the three letter words"), *ubhubhane* ('the destroyer'), "the father, son and holy spirit"; "Yizo Yizo" ("It's it") are used in preference to the terms HIV and AIDS (Marcus, 2002). Some view HIV as a punishment sent from God to teach people the wrongfulness of their ways (Wild, 2001). Others view it as a form of poisoning, bewitchment, *muti*, or the result of avenging ancestral and other spirits (Marcus, 2002). People dying of HIV/AIDS are regarded as

having suffered a “bad death” that brings shame, embarrassment, isolation and guilt (ibid.). These emotions severely complicate the other more commonly-held emotions associated with bereavement.

Although the situation is beginning to change in a positive direction, many HIV+ people maintain secrecy, fearing that disclosure of their HIV status will not only harm them but their families as well (Foster & Williamson, 2000; Wild, 2001). The shame and embarrassment surrounding HIV/AIDS seems to stem largely from the belief that those who are HIV+ have been behaving immorally by engaging in unregulated sexual intercourse (Marcus, 2002). To avoid discrimination, the veil of secrecy can be stringently maintained by the individual and family with the result that many children are lied to by their parents and family about the cause of the illness and death (Cook, 1998; PACT, 2002; Refugee Studies Centre, 2002). Whilst the ‘conspiracy of silence’ is usually maintained to protect children and families, it can leave AIDS orphans feeling different, alienated from their peers and unable to confide in anyone for fear of bringing or increasing shame to themselves or their families (Giese et al., 2003; McKerrow, 1995; Pivnick & Villegas, 2000; Wild, 2001). These same children are also likely to be the victims of incremental discrimination due to the stigma of being poverty stricken and poorly educated (Brooks-Cole & Duncan, 1997). Children in poverty-stricken communities begin their life journey carrying the burden of numerous risk and adversity factors. The larger picture of change and adversity brought about by the HIV/AIDS pandemic gives an indication of the scale and proportions of the problems. There is however, a more personalised psychosocial face that will be discussed in the following chapter.

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Chapter 3:

The Psychosocial Impact of HIV/AIDS: Walking the Road

Many psychosocial issues associated with HIV/AIDS, transcend economic, political and other macrosystemic boundaries, as children made vulnerable by the vicissitudes of this pandemic become embroiled in a downward spiral of distress and difficulty. The psychosocial impact of HIV/AIDS begins when the parent or primary caregiver becomes HIV infected and continues long after the death of the parent/s. Far from offering the stability and security that children need through childhood, these children's circumstances are continuously in a state of flux and change as their situations alter with each unfolding process. One method of understanding the psychosocial impact on children and their families is to 'walk the road' or follow the life path, considering the impact at each successive stage that the child will probably experience (Foster & Williamson, 2000; Schoeman, Killian & Hough, 2000). The stages most likely to be encountered by the child 'walking the road' include:

- (i) The emotional impact of HIV infection that begins as the parent realises that they may be HIV+ and suffering with a stigmatising terminal illness. Alternatively the child may fear that the parent will or is becoming ill, as the child may notice that the parent suffers with frequent ailments, aches and pains.
- (ii) Witness and/or participate in the home-based care of sick and dying parent/s and family members and becoming aware of the profound and distressing problems that accompany the severe physical debilitation associated with AIDS-related illness and death (Andiman, 1995, in Wild, 2001);
- (iii) Experience the death of beloved parent/s and other family members.
- (iv) Adjust to the changes consequent to the death of a parent. This usually involves decision-making about the future care and custody of the children, sibling dispersal, inheritance issues and the impact of multiple losses.
- (v) Children may need to adjust to new home and/or care arrangements that may be very different to their familiar routine, neighbourhood, school, etc. They may be placed in *de facto* foster care, institutional care, live in child-headed households, or they may fall through all of the community safety nets and drift to the streets due to abandonment or exploitation.
- (vi) Many children will also be HIV infected and experience the major physical, social, emotional and behavioural consequences of suffering with a terminal illness.

3.1. The emotional impact of HIV infection:

In high HIV prevalence communities, individuals are likely to live with intense anxiety, distress and denial before the actual diagnosis is made. In fact, despite the availability of VCT, many people choose not to avail themselves of this facility, feeling afraid that the test will confirm their worst fears and bring stigma and shame (van Dyk & van Dyk, 2003). In addition, some people will use the defence mechanism of denial to dispute the validity of an HIV+ diagnosis. Kubler-Ross (1981) views

denial as a normal process in accepting one's own impending death and given the terminal nature of an HIV diagnosis, for many denial may be regarded as a normal process.

Using the theoretical work of Moos and Schaefer (1984) on illness-related psychological tasks, Weitz (1989) conducted an interesting qualitative study to identify the processes of adaptation required by an HIV+ individual in preparing for and coping with terminal illness: (i) dealing with the physiological consequences of the illness, including a variety of symptoms and pain - with HIV related conditions, these can be difficult to identify due to the slow, insidious onset of symptoms; (ii) dealing with treatment, side effects and hospitalisation; (iii) developing and maintaining good relations with health care providers - the fact that formal health care providers are unlikely to be involved in direct care provision and that one is likely to rely on either family members or volunteers from one's own community, adds to the complexity of the dynamics in this regard; (iv) maintaining emotional equilibrium - a particularly difficult process for parents of young children; (v) maintaining a sense of self, mastery and competence; (vi) maintaining good relations with family and friends; and (vii) preparing for future exigencies including death in a culture that holds that it is unacceptable to prepare for, or even to talk of, one's own impending death.

Weitz's (1989) study found that generally people began experiencing symptoms, but using the defence mechanism of denial, delayed going for VCT, as a means of delaying the realisation of the feared outcome and the associated stigmatisation. The emotional reactions associated with receiving a diagnosis of a terminal (and stigmatising) illness usually start a psychic process that will enable an individual to begin the process of accepting death (Follansbee, 1996, in Shernoff, 1999). However, it is probable that this process will be highly complicated by the myths, mistrust, confusion and social suspicions associated with HIV/AIDS. Feelings of guilt, shame, anxiety and distress are likely to be exacerbated. This, in turn, could negatively affect the way in which an individual and family accept the diagnosis.

Being diagnosed as HIV+ may result in the dissolution of marriages and partnerships out of fear of infecting, or stigmatising a sexual partner (Aggleton & Warwick, 2003; Baylies & Bujira, 2000; du Plessis et al, 1995; Gilborn & Nyonyintono, 2000). HIV+ women are placed in a particularly tenuous position as their HIV+ status may result in them not being able to find a marriage partner, or if married, being forced into separation or divorce (Aggleton & Warwick, 2003). Therefore, the fear of being diagnosed HIV+ may lead people to either prefer not to go for testing, or if tested, not to disclose positive seroprevalence status, even though they are in desperate need of emotional and social support (Cohen, Underwood & Gottlieb, 2000; Pegengnat & Szapocznik, 2000).

In dealing with the anxieties and adaptation required during this initial stage of uncertainty, it is likely that children will suffer in the form of insecure attachment relationships (Mädörin, 2000;

Wild, 2001). The awareness that one could be HIV+ is often associated with the start of a long period of instability during periods of hospitalisation and illness of the parent. During this time of emotional and physical stress, children experience erratic parenting and their routines may be regularly disrupted (USAID and the Synergy Project of TVT Associates; 2001); The parent/s may (i) not be emotionally available to their children as they deal with their own emotional turmoil; (ii) indulge them in an attempt to compensate for their own feelings of guilt and shame and in a desire to be remembered as a loving, as opposed to disciplining, parent (Hudis, 1995); (iii) consciously or unconsciously emotionally distance themselves in order to both protect the child from the parent's current emotional turmoil as well as the child's future feelings of loss and grief when the parent dies; or (iv) oscillate between these various emotional states. The incremental impact of the emotional vasillation of the parent as s/he adapts to the illness and the diagnosis will create distress and instability for children.

3.2. Illness, home-based care and witnessing physical debilitation:

The prolonged period of illness with the associated vulnerability to opportunistic infections such as TB and pneumonia, creates an emotional roller-coaster for the children. As the parent/primary caregiver suffers from increasingly frequent bouts of illness, caring for the sick may absorb all of a family's emotional and physical energy over many years (Gilborn & Nyonyintono, 2000; Karlenza, 1998). Children may be neglected. They frequently shoulder the burden of caring for the sick and dying, as the adults in the household are too old, infirm, or committed to other activities, to manage without the assistance of the children (Ayieko, 2003; UNICEF, 1999). Simultaneously, much of the family's financial resources could be depleted with costs being incurred as people seek treatment from both western and traditional healers (Fox et al., 2002; Marcus, 2002).

During this stage, children are likely to develop various symptoms in reaction to the degree of emotional distress pervading the home (Fox et al., 2002). One New York City-based study showed that 40 percent of the children (ages 8-12) whose mothers had late-stage AIDS had elevated symptoms of mental health problems, regardless of the children's age or gender (Landman, 2003). This study showed that high maternal distress, poor parent-child relationships and stage of illness were associated with behavioural problems.

As the illness progresses, ailing parents as well as other adults within a household (who are probably themselves in emotional turmoil or grieving) are likely to become progressively less able to discipline and supervise their children (Hudis, 1995; Wild, 2001). Children need routine and discipline to provide security and predictability about the world (Erikson, 1963; Mäddörin, 2000; Refugee Studies Centre, 2002). Routines and their associated security are particularly upset when several family members are infected, become ill or die. The literature suggests that children are likely

to suffer with internalising disorders as they become anxious, depressed and socially alienated (Corr, 1996; Lutzke et al., 1997; Tremblay & Israel, 1998),

During this stage children experience social suspicion and increasing ostracism as rumours about the possible cause of the illness begin to spread around the village/community (Fox et al., 2002). There will be financial deterioration as the economically-active members of the household divert energies to HBC and money is spent on seeking a cure. Family lives are thrown into turmoil as people begin to have differing views about when and where to seek help. The burden of caring for the ill can be particularly draining of emotional and other resources, since various additional household responsibilities arise. This in turn creates emotional distress in the children (Brown & Lourie, 2000; Cook, 1998; Mäddörin, 2000).

Experiencing the illness of a parent has a profound effect on a child. The HBC of the parent, immediately before the death, exacerbates the child's feelings of guilt, responsibility and fear, even though it also affords the child the opportunity to engage in active-coping strategies. It is physically and emotionally draining to care for someone who is seriously ill at home and when faced with a lack of resources all family members are likely to become fatigued, irritable and frustrated.

As the dying person realises that death is near, they may be placed in an emotional and cognitive quandary. Generally there is no social or cultural sanctioning for speaking about impending death (UNAIDS, 2001), as many African people still hold a superstitious belief that speaking about death, 'invites death in' and indicates that one wants the dying person/oneself to die (Personal communications, 2002). In many communities, speaking about death may also be perceived as being indicative of participation in witchcraft (Cook, 1998; Foster & Williamson, 2000). Even in the terminal stages of an illness, conversations usually revolve around finding cures (Marcus, 2002).

The custom of not speaking about death has various adverse consequences for children: (i) preparation for death is minimal and very little is done to prepare a child for the impending death of his/her parent/primary caregiver; (ii) succession planning is minimal - only 2% of Zimbabwean families wrote a will (Drew, Foster & Chitima, 1996, in Foster & Williamson, 2000); and (iii) it denies the dying individual the opportunity to prepare for his/her own death (Ayieko, 2003). Perhaps most importantly from the child's perspective, it leaves the child feeling confused, scared and anxious, as s/he realises that the parent is critically ill and yet no-one explains what is happening, or why it is happening, leaving the child at the mercy of his own immature cognitive and emotional processes. Not being able to speak about death also impedes the process of preparing for one's own death emotionally, socially and attending to post-death issues such as guardianship and inheritance (UNICEF 2000a).

3.3. Impact of parental death:

The death of a loved one is an ubiquitous human experience that everyone will face at some point in their lives (Bonann & Kaltzman, 1999). Grief consists of a set of individualised psychological and physiological reactions to the death, normally considered to include deep sadness, painful awareness of loss, physical distress, reminiscence, anger, anxiety, depression, risk-taking behaviours and despair (Killian & Perrott, 1994). On the other hand, mourning represents the conventional behaviour determined by the customs of a particular society and as such it is embedded in the cultural context (*ibid.*). Therefore, death of a family member is simultaneously a social and a private event (Marcus, 2002). The death of a parent from an AIDS-related illness is especially difficult because of the stigma and real-life consequences for the children (Lin, Rotheram-Borus & Stein, 2001; Reyland, McMahon & Higgins-D'Alessandro, 2002).

A family member's death can be the catalyst that propels children into escalating turmoil. Irrespectively, the psychosocial needs of children generally receive lower priority than the pressing need to organise the funeral and follow customary practices in order to regain or maintain status in the community. Funerals tend to be lavish, costly ceremonies (Marcus, 2002), that fail to take into account the economic needs of the bereaved family. Despite extreme poverty, funeral expenditure is perceived to be essential in order to send the deceased to ancestors with goodwill and peace (de la Harpe et al., 1998).

Although in some areas, customs are beginning to change, it is highly unusual for children to be told of a parental death or to participate in the funeral or other grieving rituals (Akukuwe, 1999). The impact of excluding children from these rituals has particularly negative effects because the death and the vigil usually occur in the family home. The grave is usually within the homestead. Nevertheless, in the mistaken attempt to protect children from the harshness of death, children are (i) told untruths about the whereabouts of the deceased (e.g., "Your mother has gone to Johannesburg"), (ii) told to stop asking questions (e.g., "Go and play", "Show respect"), or (iii) an elder will whisper into the sleeping child's ear that their loved one has died (Personal communications, 2002). Very young children are unlikely to be told of the death. Even in the long term, relatives are inclined to take in very young children and never directly reveal their orphan status to them (Mann, 2002).

Although there are tribal and community differences, children who are old enough to realise what is happening (culturally estimated to be 4 years and above) are not allowed to see the deceased, the coffin, or the grave and are prevented from participating in funeral or burial rites (Mann, 2002, p. 10). By force of circumstances, these customs are changing. Nowadays it is often only the children who have the strength to carry the coffin (*ibid.*). However, they are still infrequently told whose coffin they are carrying and they usually only learn of their orphan status from peers, other children in the household, neighbours, or at times, in fits of rage by exasperated caregivers. Once the child

has discovered their orphan status, they usually do not disclose this information to primary caregivers, for fear of seeming to be ungrateful to their new caregivers or disrespectful of the deceased (ibid.). Older children generally retain their family name, whereas younger children frequently informally adopt the name of the caregivers, leading to bureaucratic difficulties when they need to apply for birth, life, or death registration and certificates.

These customs have several consequences. Firstly, it could leave children feeling confused and unable to understand or participate in the grieving and mourning processes. Secondly, it may increase the child's frustration at not being able to understand and being denied any socially-approved mechanism through which clarity can be sought. Thirdly, it strongly demonstrates to the child that it is unacceptable to discuss or express feelings of grief and sadness. The absence and impossibility of dialogue may precipitate children feeling alienated and isolated, thereby contributing to the self-perception of being different and a burden on one's caregivers (Brown & Lourie, 2000; Foster et al., 1997a; Schoeman et al., 2000).

The loss of a parent is of immense significance for a child (Corr, 1996; Lutzke et al., 1997; Tremblay & Israel, 1998). With parental death, children lose the love and nurturance previously provided by their parent/s. The death of a mother is likely to have profound psychosocial consequences since it may signify the loss of the most secure attachment figure in a child's life. The loss of a father often means the loss of income and results in increased economic deprivation (Foster & Williamson, 2000; Mádörin, 2000). Parental death is also frequently accompanied by other major changes in children's lives. The psychological impact of parental death can emerge at any time, even years later and can greatly reduce a child's ability to integrate into family and social activities (Fox et al., 2002, p. 12). Households may fragment or re-organise. Siblings may be sent to live with different members of the extended family. Interestingly, sibling dispersal is a predictor of emotional distress in children (Nampanya-Serpell, 1998). Family roles may change with children taking on adult responsibilities (Reyland et al., 2002).

Individuals vary in their response to the death of a significant other (Fox et al., 2002). The bereavement response will be influenced by closeness of the relationship with the deceased, the personal concept of death and previous experience with death (Kandt, 1994). The psychosocial impact of losing a parent is no less significant on children and youth in developing countries than in the developed world. Nevertheless, the pressing needs for basic survival tend to dominate family concerns and priorities where the major focus is usually on meeting the basic survival and material needs of children.

Children live with extreme distress and uncertainty while they experience the full impact of death. A qualitative study conducted in rural Zimbabwe with AIDS orphans revealed that the areas of concern for the children themselves included feeling different from other children, high levels of

stress, stigmatisation, exploitation, uncertainty about their education and lack of tangible support from relatives in the form of visits and expressed concern (Foster et al., 1997a). AIDS orphans reported that the social and self-imposed silence surrounding issues pertaining to death, reinforced feelings of grief, loss and failure since it prevented them from preparing for the inevitable death and left them feeling that they did not do enough to try to prevent the death (ibid.). AIDS orphans also report more disruptions to their education (Ankrah, 1993; Foster et al., 1997; Fox et al., 2002; Gilborn & Nyonyintono, 2000), more depression (Sengendo & Nambi, 1997) and higher levels of emotional distress than children orphaned through reasons other than AIDS (Foster et al., 1997a). It seems that the loss of consistent nurturance is a critical predictor for developmental problems (Fox et al., 2002; Rutter, 1984).

Over and above these factors, AIDS orphans experience extreme poverty (Ntozi, 1997). They live in fear that they will be HIV infected (Foster et al., 1997b) and will die in similar terrible and painful ways as they have observed family members die. Many do. The distress of losing a parent can leave children feeling stigmatised, more prone to dropping out of school, socially isolated and alienated from friends, exploited through increased work loads, hopeless, fearful and anxiety-ridden (ibid.). They hold lower expectations for the future and are less likely to believe that they would be able to find employment (Foster & Williamson, 2000). In a Zambian study, 82% of primary caregivers noted that subsequent to the death of a parent, children became worried, sad, tried to help in the home, stopped playing with friends, became more solitary and fearful of new situations (Poulter, 1997),

If orphaned children are to develop the resilience they need to deal with the challenges in their lives, their psychosocial needs must receive proper and prompt attention (Cook, 1998; Mäddörin, 2000). Therefore, the way in which a parent's illness and death are handled within the family are critical to a child's future psychosocial functioning (Rutter, 1994). Psychosocial support is a mechanism through which the feelings and experiences of those children orphaned by AIDS could be ameliorated (Mäddörin, 2000).

3.4. Changes consequent to the death of a parent:

Orphanhood is not a new phenomenon. Conventionally, across time and cultures, uncles, aunts, grandparents and other members of the extended family have taken care of orphaned children. In traditional African societies, the care of children is considered to be a responsibility that is shared between members of the extended family (Ankrah, 1993; Mann, 2002; Mukuyogo & Williams, 1991). These relatives are usually well known to the child and may have been significant attachment figures for the child long before the death of parent/s (ibid.). Many African children live with various primary caregivers within the extended family. It is not unusual for a child to live in a series of different households at different stages of his/her life, even if both parents are alive (Giese et al., 2003). For example, they may live with grandmothers when they are very young and shift to live with an uncle for their primary school years and then to another relative for their secondary schooling

(ibid.). The vast majority of orphaned children live within the extended family (UNAIDS, 2001; UNICEF, 1999). A Kenyan study, for example, found that 36% of orphans lived with their grandparents, 13.5% lived with uncles and 26.6% continued to live in their original parents' house (Ayieko, 2003). In fact it seems that before the AIDS pandemic, no-one knew which children were orphans (Mann, 2002). The HIV/AIDS pandemic, against the background of extreme and pervasive poverty, has changed this scenario.

Children need the opportunity to grieve and resolve their losses both during the period of the parent dying and upon bereavement (Bowlby, 1988). There are several factors that enable a child to cope: (i) a secure relationship with the dying or deceased parent; (ii) prompt and accurate information being given to the child by the adults in the situation; (iii) participation, both privately and publically, in the grieving; and (iv) access to a trusted and significant other who can be relied upon to offer comfort and continuity of care (Bowlby, 1969; Fox et al., 2002). Perhaps the single most important factor is to speak about and prepare the child for the impending death, so that grieving in anticipation of the actual death can occur (Christ, 2001; Jewett, 1994).

3.4.1. The decision-making process:

The sheer scale of the pandemic, particularly in countries north of South Africa, has changed the traditional strategies for deciding who should take on the custodial care of orphaned children (Cook, 1998; SCOPE & Family Health International, 2001). In the most severely affected countries, most adults feel that the choice of where children will go after the death of their parents is a luxurious concern that they can not afford amidst poverty, illness and the inability of most families to support another child. Children are placed with the "best of the worst" options available to their families (Mann, 2002, p. 31). They seldom participate in the decision-making process of where they will reside, or who will take care of them (Mann, 2002; SCOPE, 2002). However it is striking that children would use very different criteria for the selection of foster parents to those used by adults (Mann, 2002).

In their qualitative study of factors that motivate and discourage people from taking in an orphaned, or otherwise vulnerable child, SCOPE - Malawi (ibid.) found the following factors were cited by adults as being significant in the decision making process: (i) lack of choice - "there is no-one else"; (ii) perceived obligation to extended family - one cannot refuse to take in the child of a relative, although this responsibility is perceived to lie most strongly with those relatives who appear to be financially better equipped; (iii) concern for the welfare of the child, expressed in statements such as "If no-one takes them in, what will become of them."; (iv) to remove a child from an abusive situation in which the child may be suffering unduly or being exploited; (v) moral obligation to comply with a dying person's wishes (at times expressed out of fear that the deceased may haunt one for not complying with his/her dying wishes); (vi) to make an investment in the child's education, such sentiment is often accompanied by the hope that either the educated child will reciprocate and

take care of the benefactor or as an investment in terms of decreasing the chances that a child will be a burden in the long term; (vii) for self-benefit: girl children are preferred as they can be of assistance with domestic work; to gain a share of the deceased's estate; or to become eligible for government grants and other forms of financial assistance; and (viii) As the child is perceived to be relatively problem-free and so unlikely to create difficulties - young children are considered more adaptable, whereas older children are perceived to be more aware of the differences between the deceased's and current household functioning and so are considered to be more difficult to handle (Mann, 2002).

On the other hand, there are various factors that discourage relatives from taking custodial care of orphaned children (Mann, 2002): (i) Poverty and general lack of resources: some families feel they simply lack the financial and material resources to take in additional mouths to feed. (ii) If the deceased parent had been on bad terms either through strong disagreements or jealousy then it is less likely that the orphans will be offered care and protection. If the orphans are nevertheless taken in, there is an increased potential for exploitation. (iii) "*Umbombo*" - a concept considered to reflect a selfish desire to hoard one's own resources for the benefit of self and one's own biological children. (iv) No perceived personal gain with the implicit belief that the child will never view them as parents, nor will they feel obligated to assist them in old age or illness. (v) If the child is perceived to be highly intelligent, or otherwise gifted, then there could be a fear that the orphan will out-shine the biological children of the family, both at school and in terms of future employment prospects. (vi) Stigmatization and discrimination associated with HIV/AIDS: if HIV+, the child will need medical care and HBC, will impoverish the family and then will die of AIDS. (vii) Orphaned children are perceived to have many problems and consequently will be more difficult. This applies especially to older children. (viii) Lack of a sense of obligation as the child is not well known to them (usually through urbanisation), or they believe the responsibility belongs to others (when there are matrilineal or patrilineal assumptions about family responsibility).

This Malawian qualitative study clearly demonstrates that adults and children use different criteria when considering care arrangements subsequent to the death of parent/s (Mann, 2002). Adults place emphasis on the financial resources and material challenges posed by taking in an additional child. They therefore expect that children will be grateful and appreciate the opportunities that are being offered and the sacrifices that are being made. Most adults predict that orphaned children will misbehave and are difficult to look after (ibid.). Children, if given the opportunity, would base their decision on emotional factors, selecting the extended family members who have previously shown them the most love, care and attention or who showed respect and kindness towards their deceased parent/s, regardless of this person's economic resources (ibid.).

Since it is the adults who make the decisions, it is largely the practical issues that decide the fate of orphaned children in poverty stricken communities. Children are not given the opportunity to express

their own emotional needs and wishes. Love, care and concern for the child is strikingly absent from the adults' list of expressed motivators for 'taking-in' orphaned children. It would seem that Maslow's (1971) hierarchy of needs may be of relevance in terms of the way in which decisions are made about the future care of the children, since without being able to meet children's physical needs, there is a perception that families would have nothing to offer orphaned children. Furthermore, many extended families have reached saturation point and feel that they can no longer continue to stretch their already meagre resources. In many communities, the extended family system is in a state of collapse and can no longer provide the safety net into which vulnerable children fall (Foster & Williamson, 2000).

3.4.2. Sibling dispersal:

Economic factors also usually dictate that siblings will be divided out between relatives (*ibid.*). The rationale given for separating siblings is based on the fact that it is more practical for extended family to take on the additional responsibility of one rather than several children. As one participant in the COPE focus group discussions said "[Choosing a place for an orphan to live] does not depend on who is who but on who has what (Mann, 2002, p. 32). However, sibling dispersal is a source of emotional distress and other problems (Nampunya-Serpell, 1998). The threat to the secure and meaningful attachment relationships between siblings is the probable cause of this suffering in both the short and long term. In addition, siblings may feel closer to one another since they know that they have faced similar circumstances and adversities, whereas friends/cousins are more likely to be perceived as being unable to understand. Siblings also provide a strong link to one's family history, can share stories and collectively develop a sense of belonging. There is a need for further empirical exploration into the role that siblings play in offering each other emotional and social support.

3.4.3. Inheritance praxis:

It is only in modern times that the death of a mother, as the primary caregiver and nurturer, has received so much attention (Foster & Williamson, 2000; Gilborn & Nyonyintono, 2000). Previously inheritance practices were largely patrilineal in nature (World Bank, 1997) so that the death of a father was significant in terms of its socioeconomic impact. Through much of sub-Saharan Africa, inheritance praxis is largely dependent upon whether (i) a society is patriarchal or matriarchal in structure; and (ii) the writing of wills has been accepted and is practised (Foster & Williamson, 2000; Mann, 2002; Ntozi & Mukiza-Gapere, 1995). Inheritance practices usually include consideration of who assumes responsibility for the children and widow, as well as who will take over the possessions, dwellings and land. Much of Africa is patrilineal in kinship structure and polygamy is widely practised in some regions (Foster & Williamson, 2000; Mann, 2002), where

widows are 'inherited' through remarriage to the brother of a deceased husband and property is inherited by paternal relatives⁹ (Foster & Williamson, 2000).

Asset stripping and property grabbing are frequent occurrences (Fox et al., 2002; Gilborn & Nyonyintono, 2000; Mann, 2002; Ntozi & Mukiza-Gapere, 1995), leaving many children and widows destitute, unless the traditional leaders intervene. Sadly in certain situations where the parent has made financial provision for the children, this may make them vulnerable to being perceived as financial assets by relatives eager to take on the care of the children simply because they bring money and other resources (Gilborn & Nyonyintono, 2000; SCOPE & Family Health International, 2001). In general however, when a parent has signed a will or indicated where the children will go, the transition into orphanhood is easier for the children (Fox et al., 2002).

3.4.4. Impact of multiple losses:

Along with the death of their parent, children frequently experience multiple losses. They lose status, opportunities, dreams and hopes for their future, economic power, home, familiar routine, structure, discipline and property. The loss of home/family is usually precipitated by the need to move and live with other families/people. This leads to loss of friendships, familiar school and neighbourhood networks as well as a sense of belonging (Hunter 1990; Hunter & Williamson, 2002; Kandt, 1994; Reyland et al., 2002; Wild, 2001). In addition, many children suffer the deaths of several family members as a result of the various modes of HIV transmission (Hunter & Williamson, 2002). The impact of these multiple losses may deprive them of their childhoods in terms of the spontaneity, playfulness and freedom that is usually associated with children.

Orphaned children, both prior to their parent/s' death and after, are at increased psychosocial risk of physical, emotional and sexual abuse (UNAIDS, 2004): (i) orphaned children are more likely to be exploited for their labour; (ii) they are more prone to enter early and forced marriage; (iii) they tend to be initiated into sexual activity at an earlier age and are more prone to being sexually abused and/or exploited due to economic pressure, loss of parental care and attention and interrupted socialisation. These factors place them at increased risk of HIV infection, STI's, tuberculosis, pneumonia and other diseases (USAID and the Synergy Project of TVT Associates, 2001, p. 12).

3.5. Impact of alternate care placements:

Upon the death of primary caregivers, decisions need to be made about who will take over responsibility for the day-to-day care of the children. Care of the children by the surviving parent is perhaps the most logical option for the on-going care and support of the children. The surviving

⁹ In Tanzania for example 97% of widows were denied the right to inherit a deceased husband's possessions and most widows had a coerced sexual relationship with in-laws (Mmari, 1995) and the sexual obligation was not related to the in-laws bearing the responsibility for either the widow or her children (Drew, Foster & Chitima, 1995, in Foster & Williamson, 2000).

parent is likely to remarry and the responsibility for the day-to-day care of the children is shared with the new marital partner (Ntozi & Mukiza-Gapere, 1995). Unfortunately the surviving parent is frequently also HIV infected, may themselves be sick with AIDS and are often too weak to fend for themselves or the children (ibid.). Furthermore few people would agree to marry a widow or widower, even if s/he is known to be HIV-, since they would be perceived to have few, if any, financial resources left after having cared for a sick partner (ibid.). Folklore and popular myths lead many people to fear for the emotional and physical safety of their children should the responsibility for their care be relegated to a step-parent after their own death. The archetype of a nasty step-mother is a cross-cultural phenomenon (Jung, 1967).

Guardianship arrangements for children are rarely formalised. Even where parents have identified a potential guardian, they rarely make this explicit or legal and in many cases do not discuss the plan with the potential guardian (Foster & Williamson, 2000). In terms of the living arrangements, the following options exist: (i) Foster care, which includes spontaneous/informal foster care with extended family and relatives, as well as the less common foster care of non-relative children. The latter is more likely to be a formal/legal arrangement in which the foster parent receives a grant to meet the financial needs of the child. Social service policies in South Africa permit people to claim foster care grants for children who are not their biological children, but when spontaneous foster arrangements are made by the extended family, they often do not know about or have access to this facility. (ii) Adoption in which all legal rights and obligations of parenting are transferred to the adoptive parent/s. However, the western concept of adoption does not feature in most African communities (Hunter & Williamson, 2002; Ntozi & Mukiza-Gapere, 1995). (iii) Institutional care in the form of orphanages/children's homes - an option internationally recognised as a last resort (Dunn, Jareg & Webb, 2003). (iv) Child-headed households. (v) Abandoned and street children.

3.5.1. Foster care:

The extended family system has always been well developed in Africa where a collective sense of identity is rooted within the extended family (de la Harpe, et al., 1998). Extended families consist of an extensive network of connections and interdependence between people, extending through varying degrees of relationship to include multiple generations over wide geographical areas and involving reciprocal obligations (Foster & Williamson, 2000). The extended family includes grandparents, siblings, uncles, aunts and cousins. Perceived responsibility for the orphaned children will be determined according to matrilineal or patrilineal cultural practice. Extended families have frequently needed to disperse over wide geographical regions as individuals seek employment or education within industrialised settings. This has created a situation in which grandparents, sick and handicapped individuals and children are left in the more rural environments. The African extended family is still the fundamental source for caring for the sick, aged, weak and helpless (Ntozi & Mukiza-Gapere, 1995, p. 245). Yet, when family members take on the foster care of orphaned

children, they too will be grieving the recent death of the child's parent who was a relative, frequently their own child.

Informal foster placements are considered normal arrangements for the care, nurturance and socialisation of children. For example, the maternal grandmother often takes on the *de facto* care and responsibility of her grandchildren, while her daughter completes her education or is employed. Dike (2001, in Burr & Montgomery, 2003) explains the situation among Xhosa families in South Africa: "when you have your first child, you are considered to be immature and inexperienced. So [your] mother will bring up the child for you and you will be there to see how ... by the time you have your second child, you actually know what goes into bringing a child up" (p. 61). Giese and her associates (2003) confirm this to be a prevalent practice throughout South Africa.

The overwhelming majority of orphans and vulnerable children reside with surviving parents or extended family, many of whom are themselves sick, dying, elderly, or incapacitated (Ankar, 1993; Cluver, 2003; Family Health International, 2001; Mukuyogo & Williams, 1999). Although foster care in many western countries takes place outside of the extended family system, this form of foster care is infrequent in African countries (Caldwell, 1997, in Foster & Williamson, 2000). The epidemiology of the pandemic suggests that approximately 50% of HIV+ people become infected before their 25th birthday and many of these will die before their 35th birthday (UNAIDS, 2001). This decimation of the parent generation will leave large numbers of children raised by grandparents or siblings.

In fact, it is the grandparents who are most likely to become the spontaneous caregivers of their grandchildren, especially in areas where the AIDS pandemic is the most severe and where the extended family has been seriously weakened (Fox et al., 2002; McKerrow, 1997). In the current context, the majority of foster parents are the grandparents of the orphans: 43% of the guardians of orphans were over the age of 50 and 31% of orphans were in the care of their grandparents (Hunter, 1990). Grandparents are seldom in a position to meet the educational and material needs of their children (Ntozi & Mukiza-Gapere, 1995). Furthermore, due to their age, they may not have the energy and physical fitness needed to actively engage with many of the functions and responsibilities of effective parenting. Rather the new-found caregivers are likely to be elderly, impoverished, struggling to meet the basic needs on their meagre pensions and are themselves frequently in need of care and support.

The focus on foster care as the preferred option of child placement originated with the seminal work by John Bowlby (1988) on maternal attachment and psychosocial consequences of maternal deprivation. The western world began to strongly favour child care arrangements that mirrored family life (Burr & Montgomery, 2003). Adoption and fostering were seen to be more beneficial forms of child placement in situations where the nuclear family had collapsed (Dunn et al., 2003).

By contrast, the orphanage or children's home is the least favoured option. In their survey of 12 European countries, Berridge and Brodie (1998) found a trend to close down large orphanages and small community-based children's homes were only being used in the most extreme situations. Wherever possible, children in Europe are placed in foster care or adoption 'in the best interests of the child' (Goldstein, Freud & Solnit, 1973). This trend is rooted in the belief that children need the experience of family life for optimal development (Burr & Montgomery, 2003).

However, not all foster placements are ideal. Many foster parents and children experience significant distress and disruption. Children who have led disrupted lives find it particularly difficult to settle and form attachments within their new families. Twenty percent of children in foster care in the United Kingdom have three or more different foster placements over the course a single year (Brindle, 2001, in Burr & Montgomery, 2003). Multiple foster placements are shattering experiences for children as they signal a deeply-felt failure to be accepted and integrated within a family context.

The difficulties experienced with foster care placements in Europe are mirrored elsewhere. Most extended families absorb orphaned children even when their own economic, emotional and social capacity has already been severely over-extended (Burr & Montgomery, 2003; Family Health International, 2001; Ntozi & Mukiza-Gapere, 1995; Richter 2003; UNAIDS, 2001; Wild, 2001). The need to regularly accommodate additional sick family members and orphans, in combination with the fact that the number of functional extended family systems is being steadily diminished, has placed unbearable strain on extended families in the most severely affected countries (Brown & Lourie, 2000; Foster & Williamson, 2000; Ntozi & Mukiza-Gapere, 1995). As a result, children who have recently experienced the death of their primary caregivers, enter situations that are already experiencing significant distress and profound levels of daily stress.

Research also indicates a tendency to discriminate against, or exploit, orphaned children whether they are in the foster care of relatives or non-relatives (Mann, 2002; Ntozi & Mukiza-Gapere, 1995). Relatives may suspect that orphaned children are HIV+ and therefore fear that they or their biological children will become infected. This may lead to orphaned children being isolated away from their foster family in order to avoid the family becoming infected (Mann, 2002; Ntozi & Mukiza-Gapere, 1995).

In addition, in her Malawian study, Mann (2002) found that adult guardians articulate a strong belief that orphaned children have many behavioural problems, are difficult to look after and are ungrateful. Simultaneously, orphaned children in the foster care of extended family members (especially non-grandparents) reveal a startling pattern of abuse and discrimination within their new-found families. It would appear that a vicious cycle of misunderstanding exists. Orphaned children enter the homes of new-found guardians having already been exposed to high levels of distress, stemming from prolonged periods of witnessing, caring for and eventually losing one or both

parents, in addition to being victimised by the stigma that surrounds HIV/AIDS and orphanhood. Foster parents believe that they have been benevolent in offering shelter and care, despite the numerous explicit and implicit challenges and so they expect the children to behave well, be helpful, be grateful and not complain. Foster parents also tend to discourage children from remembering and discussing past stressful and traumatic life experiences. Conversation and reminders of deceased parents are deemed by their new-found foster parents, to be especially detrimental. They prefer the child to accept the finality of the parent's death, not dwell on past circumstances, adjust to the new circumstances and get on with life. From the children's perspective, there is a profound sense of isolation as it seems to them that no-one is interested in their emotional state or pays attention to their special needs for love and attention as they work through their feelings of grief and sadness. The feeling of loneliness may be compounded by feeling different to the other children in the family, who may also be perceived as being treated more favourably. They may act out their feelings by being rude or behaving inappropriately or by withdrawing from their foster family. This results in the vicious cycles in which the guardians feel unappreciated and therefore less inclined to be supportive and kind and the children feel sad, angry, alone and unjustifiably discriminated against (Mann, 2002). It is extremely difficult to break or change this cycle of negative person-to-person interactions.

An additional factor is the unfortunate perception held by many community members that access to foster care grants is limited to placements of children with non-relatives. Therefore the extended family is likely to struggle economically without the social service support to which they are entitled. The lack of financial resources may create a situation in which the extended family resent the consumption of limited resources by sick relatives and additional children. This has negative psychosocial consequences for the children and for members of the extended families who may feel guilt about feeling resentful and having negative attitudes.

Despite all of these difficulties, many extended families are still the primary caregivers for orphans, even in the face of heavy financial burdens (Ntozi & Mukiza-Gapere, 1995). However, failure to harness coping resources and support children through the adversities that they face is likely to have long-term negative impacts for both children and families. Orphans, whether they live within or outside of the extended family, are prone to discrimination, exploitation, neglect, abuse and limited access to health, education and social services (UNAIDS, 2001). For example, fostered children in west Africa experienced higher mortality rates due to poorer levels of general care, increased rates of malnutrition and reduced access to modern medicine (Bledsoe, Ewbank, & Isiugo-Abanihe, 1988; Orin, 1995, in Foster & Williamson, 2000). Orphans face a bleak future if their primary caregivers are not given additional economic, social and emotional support. In addition, communities can offer support and encouragement to extended family. A feasible way forward is to mobilise and strengthen community responses (Germann & Mäddörin, 2002; Hunter & Williamson, 2002).

3.5.2 Institutional care:

It is the writer's experience that sick and dying parents often request that their children be placed in orphanages in the belief that the children will receive food, clothing, health care, education and shelter. However, the widely accepted western and professional viewpoint is that institutional care should be a last option for children (Burr & Montgomery, 2003; Dunn et al., 2003). Families do not cease to exist when parents die (Reid, 1993, in Ayieko, 2003). Research over many years has shown that institutional care¹⁰ fails to meet the developmental and long-term needs of children (Bogen, 1992; Burr & Montgomery, 2003; Goldstein et al., 1973; Rutter, 1984). Children's homes have generally failed to fulfil the psychosocial needs of children due to their inability to offer the love, care and personal attention that children need (Bogen, 1992). In addition, placement in an institution means that children probably lose contact with their extended family, making adjustment to society on attainment of the age of maturity especially difficult and tends to increase the child's long-term vulnerability.

However, it seems that children's homes in countries that have widespread poverty are better equipped to meet children's physical, educational and material needs. This may be at the cost of stability within the broader community (Burr & Montgomery, 2003; Tolfree, 1995). Hopkins (1996) found that Vietnamese parents tend to view children's homes as offering their children considerable advantage by virtue of the fact that they provide more opportunities and greater safety. The establishment of children's homes can have the unintended consequence of breaking-up families by undermining extended family and community structures, responsibilities, obligations and the child's sense of belonging to the wider community (Hopkins, 1996). Tolfree (2004) argues that the western literature has romanticised cultural practices in terms of the shared communal ideology and that many families exploit non-biological children and take advantage of the opportunity to abdicate responsibility when children's homes exist in their area. The option of a children's home placement provides an instant solution even in situations in which other, more appropriate, family-based care might be available (Tolfree, 1995, p. 38). However, this harsh criticism (Burr & Montgomery, 2003) fails to take into account the economic reality of many families who live in dire poverty and seek 'only the best' for their children, yet realise that they are barely able to meet their own needs, never mind the needs of their children. Providing children with an education, a reasonable diet and shelter is an attractive option.

Given the scale of the HIV/AIDS pandemic, children's homes are not appropriate as a frontline response since the running costs of institutional care are astronomically high (Hunter & Williamson, 2002). Ugandan cost comparisons have shown that the operating costs of children's homes were 14

¹⁰ The terms institution and orphanage tend to be used interchangeably. However, in the west, the term 'orphanage' is used in a historical context, having been replaced in professional literature with the term 'children's home'. Orphanages have attracted derogatory connotations as they are associated with outdated, unhygienic, poorly supervised environments. The frequent use of the term when perusing the literature pertaining to the HIV/AIDS crisis in Africa is thus most unfortunate.

times higher than those for community care (*ibid.*). The ratios for institutional care compared with community care range from 20:1 up to 100:1 across different regions (Hunter & Williamson, 2002, p. 12). This is supported by a study on the survival rates of 174 Malawian and Kenyan AIDS orphans over a five year period, where survival rates were only 70% at age 3 years and 29% at age 10 years (Nerlander, Nathan, Dixon, Barnabas, Wholeben, Musoke, Palakudy, D'Agostino & Charkraborty, 2002). These authors conclude that children who remain within the community are exposed to additional risks associated with food insecurity, exposure to TB infections and the lack of provision of nutritionally fortified foods on a regular basis. The most striking conclusion arising from these figures is that insufficient funds are being directed to community care of orphans. It is entirely possible that if more resources were channelled to supporting children and community-based programmes, then the outcomes for the children would be considerably improved.

Despite professional consensus that institutionalised care is neither a developmental ideal nor a financially viable option (UNAIDS, 2001), many forms of institutional care for children have sprung up to accommodate AIDS orphans. Most of these represent crisis responses to the emergency. The long term impact on children who spend considerable portions of their childhoods in institutional care still needs investigation. In the meantime, it seems expedient to devote resources to strengthening families and communities to care for orphans and other vulnerable children (UNAIDS, 2001). Save the Children, for example, has drafted policies that strive for a global reduction in the use of institutional care, in combination with the growth of durable and sustained forms of community care (Dunn et al., 2003). They argue that using orphanhood as the criterion and target of emergency relief, directs attention away from some of the real issues that adversely affect children, such as the needs for protection and survival. They maintain that efforts should be directed towards building capacity within communities and sensitising community members to the needs and rights of children to grow up within family and community structures (Hunter & Williamson, 2002). This dissertation evaluates a community-based programme that implements these principles.

3.5.3. Child-headed households:

There is a growing trend towards orphans caring for themselves (Fox et al., 2002). In circumstances in which the child is not known to the extended family, or where the extended family has already been considerably eroded in its ability to care for additional children, some households may be made up of children living alone (Ali, 1998). These usually take the form of sibling-headed households in which an older sibling takes on the care and responsibility of his/her younger siblings (Ntozi & Mukiza-Gapere, 1995). The older sibling who is sprung into the role of primary caregiver may be below the age of eighteen years (Barnett & Blaikie, 1992). Child-headed households are therefore defined as groups of orphaned children (brothers and sisters, sisters or brothers only) living under a caregiver who is under the age of 18 years (Ayieko, 2003).

Members of the extended family may decide to leave children in child-headed households in circumstances in which (i) relatives are reluctant to foster older children who are perceived to be least likely to adapt to new circumstances; (ii) there is a teenage child who is already experienced in childcare; (iii) there are relatives living nearby who could play a supervisory and supportive role; (iv) siblings strongly express a desire to stay together in their parents' home; (v) in compliance with a dying person's wishes - some people specify on their death beds, or in their wills, that their children are not to be removed from the homestead, so relatives may be afraid of the evil spirits of the deceased parents and ancestors if they take action contrary to the deceased's will (Ntozi & Mukiza-Gapere, 1995).

Children themselves may be instrumental in the decision to remain in a child-headed household: (i) orphans fear that if they leave their parental home, their land would be seized by landlords, traditional leaders, neighbours, or relatives and they would lose access rights to the property and the belongings of their parents (Foster & Williamson, 2000); (ii) moving to the homes of extended family would involve them moving to unfamiliar territory that is perceived to be too overwhelming and difficult (Wild, 2001); (iii) parents had expressed a wish that their children remain on their ancestral land (Ntozi & Mukiza-Gapere, 1995); (iv) to escape perceived and/or predicted lack of care and the potential for exploitation. Mann's (2002) study found that many children feel that if the prospective foster parents had shown little respect or care for their ill and dying parent, then there is little chance that they will be loving or supportive. Thus, the children may decide to try to cope alone, without the support of the extended family.

In most circumstances, this arrangement is far from ideal. Older children lack the guidance and support that they developmentally still need. They take on age-inappropriate responsibilities and often suspend their own life goals in their endeavour to provide care to their younger siblings. This inevitably leads to frustration and resentment. The younger children may not get the psychological and material support they need thereby placing them at increased risk of health, psychological, behavioural, emotional and economic problems in the future (Ali, 1998; Fox et al., 2002; Ntozi & Mukiza-Gapere, 1995).

3.5.4. Abandoned and street children:

Some children fall through all of the social safety nets and drift onto the streets (Cluver, 2003). They may literally be abandoned and have no option but to live on the street. Alternatively, they may choose to live in the streets most of the time and periodically return home. Others run away from their relatives' homes to escape exploitive or abusive situations (Ayieko, 2003). Property-grabbing by landlords, relatives and others may literally leave children with nowhere to live (Ntozi & Mukiza-Gapere, 1995). In an endeavour to protect children, there has been advocacy for the urgent need for laws that recognise widows' and orphans' rights to their husbands' or fathers' property in order to

deal with this problem (Hunter & Williamson, 2002; UNAIDS, 2001). This is usually combined with campaigns to encourage people to write wills (Ntozi & Mukiza-Gapere, 1995).

Children who have had little regular contact with their extended families and so are relatively unknown to them, are at greater risk of being abandoned (*ibid.*). Children of migrants and refugees, as well as those who live in urban areas or on commercial farms, are likely to grow up with very little contact with relatives and so are not well-known to members of their extended families. These children are at greatest risk of being abandoned by the extended family (Foster & Williamson, 2000; Fox et al., 2002).

3.6. The HIV+ child and children's understanding of illness and death:

Since the beginning of the pandemic more than 5 million infants have become infected with HIV, with an estimated 1,500 children becoming newly infected with HIV every day (UNAIDS, 2002). 90% of new infections are a result of MTCT (UNAIDS, 2001). The remaining 10% become infected through contaminated blood, use of contaminated instruments, or through sexual abuse and exploitation (UNAIDS, 2002). Vulnerable children often live in precarious economic and social circumstances, making them especially susceptible to HIV infection (UNAIDS, 2004). All children from families affected by HIV/AIDS have an increased risk of HIV infection. In fact, the general pattern seems to be that HIV+ children acquire the virus from their mothers peri-natally and usually their father is also infected (Fox et al., 2002), but in 60% of cases the father dies first, leaving the mother and children in a highly tenuous position (Ayieko, 2003). The psychosocial status of orphaned children places them in danger either through their own risky behaviour (perhaps due to low self esteem) or as a result of sexual exploitation by others.

HIV infection is a major contributor to childhood diseases and mortality. The progression of HIV disease in children infected through MTCT appears to either (i) have a rapid progression with the child becoming symptomatic and very sick in their first few months and usually dying before age 2 years; or (ii) have a slow progression with children remaining asymptomatic or experiencing less severe symptoms and surviving to the next developmental stages (Giese, 2002). Poorer prognosis is associated with lower socio-economic status and poor nutritional status, amongst other viral-related factors (*ibid.*).

Children who are HIV+ suffer with the same common childhood illnesses, however these childhood diseases occur more frequently, are more severe, last longer and their response to treatment tends to be poor (UNAIDS, 2002). In high prevalent countries, more children die from these diseases even though the same illness may be regarded as a minor childhood malady in other countries. Inadequate or overstretched health services frequently are accompanied by lack of immunisation facilities leading to many children dying from diseases such as measles, polio, chickenpox and mumps. Early

treatment of opportunistic infections can significantly improve the quality of life, relieve suffering and assist in the practical management of the disease.

In the western world, MTCT has almost been eliminated (UNAIDS, 2001) through the use of highly active antiretroviral therapy (HAART). HAART can also effectively enable HIV+ children to enjoy a prolonged lifespan and a better quality of life despite suffering with a chronic disorder (UNAIDS, 2002). However, in the countries where children most need this treatment regimen, children are likely to be denied access to treatment, even though the cost of such treatment has been reduced from previously exorbitant levels (UNAIDS, 2002).

There are various strategies that can reduce the impact of HIV on children: (i) Awareness of a possible HIV infection enables caregivers to become informed that the child will not necessarily die early and that with good care and early treatment of the HIV infection and the related opportunistic infections, the child can survive. A critical factor in this regard is to facilitate psychological attachments being formed. (ii) Early diagnosis combined with good quality care and support can enhance survival and quality of life. (ii) All children born with, or suspected of being HIV infected, should receive early vaccinations for measles (with an additional dose at 9 months of age), hepatitis B, injectable polio vaccinations (as opposed to the oral form) and pneumococcal vaccine can be administered to children over the age of 2 years. If a child is suspected of being HIV+, the BCG (for tuberculosis) and yellow fever immunisations are contraindicated and should not be given (UNAIDS, 2002). It is however known that HIV+ children exhibit a weak response to vaccinations, but the inoculations appear to be preferable to leaving them without this coverage (UNAIDS, 2002). (iii) Well nourished HIV+ children have fewer infections and their progress from HIV to AIDS is considerably slower (*ibid.*). Failure to thrive is one of the first signs of HIV in children. Vitamin A seems particularly useful in reducing morbidity and mortality. At a national level, the implementation of Vitamin A supplementation is a cost-effective strategy of intervention (*ibid.*). (iv) Basic drugs for treating common childhood infections such as pneumonia, sepsis and fungal infections alleviate pain and prolong life. For terminally ill children, adequate palliative treatment is necessary for pain relief and the symptomatic treatment of diarrhoea and respiratory symptoms (*ibid.*). (v) Recognition of the socioeconomic and psychological problems requires a multi-disciplinary approach in which medical practitioners, family and community members become sensitised to both the psychosocial and physical needs of children (Germann & Mäddörin, 2002; Shute & Paton, 1992; UNAIDS, 2002). UNICEF (2003) recommends a crisis intervention strategy for HIV+ children that includes supplemental feeding, Vitamin A distribution, de-worming, measles immunisation and provision of adequate water and sanitation.

The psychological response to illness and death in children, both in terms of personal and family experience, will be discussed in Chapter 5. Little is known about how children who are suffering with a terminal illness in the midst of a pandemic cope or understand the illness. The issues are

compounded when a child is HIV+ since the child is likely to experience (i) extreme isolation and rejection, (ii) terminal illness that swings through periods of frequent illness, perceived recovery and extremely debilitating symptoms, and (iii) need to develop an understanding of the illness and death, both in terms of one's own future and seeing death all around one (Fox et al., 2002). The lack of access to treatment programmes is an especially difficult dimension that challenges the coping of both the children themselves and their primary caregivers. In the absence of treatment regimens, perhaps Bluebond-Langner's (1978) concept of children acquiring information within western medical facilities, is replaced by observing people who are ill and dying in one's own community. This is a harsh way of educating HIV+ children about their own potential future.

3.7. Preventing HIV infection in children and youth:

There is little doubt that children need to be made aware of how to protect themselves from the disease. Children are frequently actively engaged in the HBC of dying family members (Cook, 1998; Kelly, Ntlabati, Oyosi, van der Riet, & Parker, 2002). Sexual activity may be coercive in nature (exploitation or child sexual abuse) or may be used by the child as a means of obtaining food, shelter or other favours, i.e. through prostitution (UNAIDS, 2001). Although the context varies, youth in both developed and developing countries are at risk and there is a strong need to implement and evaluate effective prevention strategies that specifically empower them (UNICEF, 1999).

Children generally have a striking lack of knowledge about HIV/AIDS, even in communities in which there have been programmes of mobilisation and information dissemination (Kelly et al., 2002; Mann, 2002). AIDS awareness campaigns have generally been viewed very critically by children who tend to focus on the hypocrisy of adults who failed to practice what they preach (Mann, 2002). Children and youth have been found to be generally more receptive to peer education and they tend to believe that behavioural change is most likely to be a result of seeing someone who is dying of AIDS (ibid.).

Around the world, health promotion campaigns have targeted youth to prevent the spread of sexually transmitted diseases and HIV infection. Despite a vast and growing literature, however, there have been very few rigorous evaluations to determine what actually works (UNAIDS, 2002). Based on practical experiences, the most effective HIV prevention strategies are guided by social learning theory, involve young people in their development, draw on a variety of instructional strategies, integrate STI and pregnancy prevention messages, provide services and recognise the influence of social norms and the media (UNAIDS, 2002; (Kelly et al., 2002). In addition, one of the most effective means of preventing HIV+ in children is to help prevent unplanned pregnancies in HIV+ women (UNAIDS, 2002).

3.8. Children and HIV/AIDS from an International Human Rights Perspective:

We are fortunate to be living in an era in which there has been a growing international focus on human rights. There are several international documents that commit to the protection of children's rights recognising that children are vulnerable members of society (Fox et al., 2002; REPSSI, 2001). The Convention on the Rights of the Child (CRC), which has been ratified by nearly all countries (USA and Somalia being the only two exceptions), has four general principles: (i) nondiscrimination; (ii) best interests of the child; (iii) survival, life and development; and (iv) participation (UNICEF, 1989). Obviously the HIV/AIDS pandemic challenges the implementation of these principles, bringing the protection and promotion of human rights into sharp focus. While this concept has been increasingly accepted in terms of adults, the protection and promotion of children's rights within the context of the HIV/AIDS epidemic has not been adequately addressed (UNAIDS, 2002). There is a huge gap between the rhetoric of human rights and the brutal reality of many children's lives (Levine & Foster, 1998).

The inherent vulnerability of children, the vast scope of the epidemic, the cascading impact on the economies of households and communities and the psychosocial consequences of these variables, calls for a human rights perspective in terms of developing and implementing appropriate responses. Human rights documents can be used to develop policies, to analyse government responses and as advocacy tools to strive towards the ideal of achieving basic human rights for all (Fox et al., 2002; Levine & Foster, 1998).

In terms of the United Nations Convention on the Rights of the Child (UNICEF, 1989), the African Children's Charter (OAU, 1994) as well as the Bill of Rights contained in the Constitution of South Africa, governments have three levels of obligation. They are expected to respect, protect and fulfill the rights that have been documented. Pervasive poverty makes this a difficult mission. However, from the international perspective these documents have powerful advocacy roles (Fox et al., 2002). Children have human rights in terms of the HIV/AIDS pandemic in three ways: (i) as HIV-infected children; (ii) in their vulnerability to becoming infected; and (iii) as children affected by a family or community members' HIV/AIDS status. Customs that place children at risk of economic or social exploitation can be changed only with the cooperation of community leaders and advocates for children (Fox, 2001). A framework of human rights for children infected, affected, or vulnerable to HIV/AIDS needs to be developed as the standard for protecting the rights of all vulnerable children.

3.9. A research and action agenda:

On the basis of the above discussion, it is clear that children, families and communities suffer in profound and complex ways that need to be contextualised, understood and used as the basis for developing research and action agendas. Consideration of the scale and nature of suffering at the

various systemic levels, logically leads to the articulation of the following principles for research and action:

- The magnitude and immediacy of the problems dictates that research needs to be action-oriented, focussing on key areas that can guide and refine programme development and implementation (Hunter & Williamson, 2002).
- Contextualisation of the problem is critical. Local experiences at grassroots may be of greater relevance than imported models of intervention. Responses to the crisis that work effectively within one context are not necessarily appropriate or relevant to another situation (Foster & Williamson, 2000; Fox et al., 2002; Hunter & Williamson, 2002; Phiri et al., 2001).
- Community mobilisation is necessary in order to access input and to involve the community in any proposed solutions or interventions. The field experience of workers is a major resource that can be documented (Hunter & Williamson, 2002), by using action research methodologies (Collins, 1999). Implicit in the concept of community mobilisation is the need to sensitise communities to the plight of vulnerable children, especially in terms of their psychosocial needs. The physical and educational needs are more evident and so are more readily addressed, even though they are more resource intensive needs. The psychosocial needs tend to be neglected, yet are critically important to address risk factors and to enhance resilience.
- Capacity building and empowerment of community members seems to be the most sustainable modality of intervention, however the means through which these are achieved needs careful consideration (Fox et al., 2002; USAID and the Synergy Project of TVT Associates, 2001).
- Ultimately strategies that enable communities, families and children to cope more effectively with the adversities of their lives would be the most beneficial and empowering as they enable individuals and communities to build resilience through harnessing their inner resources, accessing external supports and resources and developing a facilitative environment (Fox et al., 2002; Masten, 2001).

In addition, any research agenda should recognise the following assumptions:

- The way in which a problem is defined determines the solution. The problem definition is often subjectively limited by the capacity and skills of the person who offers the definition. A realistic definition of the impact of HIV/AIDS on children would encompass the holistic needs of children. However, such a broad agenda would leave one feeling overwhelmed and disempowered. Focussing on the psychosocial impact issues in this instance, therefore, simply reflects the area of interest of the current researcher and is not intended to address the complex and multiple problems that beset vulnerable children. Rather the focus is on meeting the psychosocial needs of vulnerable children within their communities.

- Research must be carried out ethically within a human rights context, even though the writer is painfully aware that this ideal is not being realised. It is blatantly obvious that children's rights are not being met in most countries, even though these countries have declared their support for human rights statutes. For example, the lack of food security, basic sanitation, health care and so forth may be points for advocacy but they are the realities that need to be taken into account when planning an intervention.
- Strategies are needed to reach the most vulnerable youth, including girls, out-of-school youth and those lacking a protective guardian or extended families. Many of these individuals are illiterate and have extremely scarce resources (UNICEF, 2000).

In summary, what is ultimately needed is a global strategy that embraces specific local responses, that recognises local ingenuity and strengthens the capacity of communities and families to provide environments in which children are protected, nurtured and given opportunities to thrive (Levine & Foster, 1998). A contribution to this problem would be to develop, implement and evaluate a programme that mobilises and sensitises communities to the psychosocial needs of vulnerable children as well as building the capacity to develop the sensitivity and skills to address children's psychosocial needs.

The theoretical contributions with respect to contextualising child development to understand the impact of risk and mechanisms through which resilience can be enhanced are useful starting points for working on this research agenda. These are discussed in the next two chapters.

SECTION II

Literature Review

The literature offers two basic metaphors for understanding child development (MacLeod, 2002). There are the well-entrenched, empirical traditions that seek universal, empirically-based theories (Dawes, 2000). These positivist models endeavour to understand causality and the basic universal laws that govern child development. Children are regarded as passive, rather mechanistic beings, who respond to outside influences. Adhering to this philosophical model, the study of child development is largely founded on the premise that the child and the social context are two distinct realities that are ontologically separate, even though they may affect one another (Dawes & Donald, 1994). Although these mechanistic models of child development are not popular in South Africa (MacLeod, 2002), they hold the appeal of setting benchmarks against which situations can be evaluated. An appropriate application of the positivist approach may be found, for example, in evaluating programmes of intervention or in advocacy for children's rights..

Contextually-based theories of child development, especially in developing contexts, challenge the concept that a child can be an object of independent scientific enquiry. They see the basis of knowledge about children as always being contextually-rooted, socially constructed and inherently has an element of uncertainty. The child exists within "an acutely socio-political, historical and ideological set of circumstances" (Hook, 2002a, pp 313). Development is seen as organismic, dynamic and fluid. It is viewed as a totality, not a collection of discrete entities or parts. Applying the principles of epigenesis and equifinality¹¹ to enhance the understanding of child development, these theoretical schools focus on the function and goal of development (MacLeod, 2002). They are more appropriate to the South African context because they take into account the political, social, gendered and cultural context within which development takes place (MacLeod, 2002; Gardiner, Mutter, & Kosmitzki, 1998).

The theories of risk and resilience are relevant in terms of understanding the developmental trajectory. Psychologically destructive and developmentally restrictive interactions between children and their environments are associated with high-risk communities (Garbarino & Ganzel, 2000; Lerner & Collins, 1996; Louw, Donald, & Dawes, 1999; Rutter, 1999; Sameroff, Seifer, & Bartko, 1997; Smith & Carlson, 1997). The social ecological theories of child development and the empirical investigations into risk and resilience variables are complementary in that both models recognise that destructive phenomena at one contextual level, can be countered by favourable patterns of interaction at another level. These favourable interchanges serve protective functions, increase resilience and increase the probability of positive adjustment for the child (Rolf, Masten, Cicchetti, Nuechterlein, & Weintraub, 1990; Stein, Fonagy, Ferguson, & Wisman, 2000).

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Epigenesis refers to the discontinuity of development; i.e. new characteristics emerge at various stages of the developmental process. Equifinality means that goals may be reached along different lines, making prediction (a mechanistic process) very difficult.

Chapter 4

The Theories of Risk and Adversity

The concepts of stress and coping, and risk and resilience have been the focus of much research and theory building over the last three decades. These two fields of study are usually regarded as being somewhat distinct: the field of stress and coping typically refers to adult adaptational processes (Lazarus & Folkman, 1984); whilst risk and resilience is commonly associated with children (Rutter, 1984; Werner, 1984). Both of these conceptually well-developed fields began by considering adversity and exposure to stress as precursors to psychological distress, with an assumption that the greater the intensity of the stress, the more severe the impact would be on an individual's psychological health. Yet, an interesting finding from these investigations was that certain individuals seem able to rise above adversity and appear to be resilient to the stressors that they experience. As a result, these fields are considered to be interactive dimensions, both of which are relevant to the current research context.

The assumption is made that nearly all children living in high prevalence HIV/AIDS communities are vulnerable. The rampage of destruction caused by this pandemic adversely affects all systemic layers of the social ecology of childhood. Whether they are directly infected, affected, orphaned, or simply reside in high prevalence communities, children are likely to experience the repercussions of this devastating pandemic. Little is known about how children are adjusting emotionally and socially to the HIV/AIDS pandemic (Cluver, 2003; Wild, 2001). Nevertheless, there is a need to develop effective intervention programmes that ameliorate risk and enhance resilience. Therefore, an understanding of the inter-related concepts of stress, risk, coping and resilience is required to operationalise these concepts for grass-roots interventions. This chapter discusses the theoretical aspects of stress and risk and considers how these concepts apply to the vulnerable children in this study. The next chapter presents the theories of resilience and ways to mitigate against risk and the stress factors to build resilience and facilitate coping.

4.1. The developmental trajectory:

Research into the etiology of pathological behaviour has consistently established a link between stress and the development of emotional and behavioural difficulties in both children and adults (Arnold, 1990; Masten, 2001; Masten, Best & Garmezy, 1990; Rolf, Masten, Cicchetti, Nuechterlein & Weintraub, 1990; Rutter, 1979; Rutter & Pickles, 1987; Smith & Carlson, 1997; Werner, 1993).

However, the association between exposure to risk factors and poor outcomes in children is not a linear one. Models of risk are based on statistical probabilities that link exposure to various adversities and a predisposition towards future development of psychopathology (Garbarino & Gandel, 2000; Garnezy, Luthar & Cicchetti, 2000; Masten & Tellegen, 1984; Rutter, 1999). In addition, it seems that for children the connection between stressful life events and adverse outcomes has repercussions on the developmental process itself (Trad & Greenblatt, 1990) and thus has the potential to alter the developmental trajectory (Rutter, 1990).

Most of the risk studies have adopted the convention of somewhat simplistically dividing the psychopathologies into two superordinate constructs in the classification of developmental psychopathology: externalised and internalised disorders (Fleming, Mullen & Bammer, 1997; Kazdin, 2000; Killian & Brakarsh, 2004; Masten, 1997; Smith & Carlson, 1997). Certain stressful events and experiences incline a children to act out their stress and developing externalised disorders such as conduct disorder, hyperactivity, attention disorders and direct or indirect expressions of aggression. Other situations are more associated with the child internalising his or her distress and developing emotional problems like depression, anxiety disorders, psychosomatic complaints and social withdrawal. Externalised disorders are more readily identified (Fleming et al., 1997). The internalised disorders are less well recognised by primary care-givers, educators and even children themselves. Therefore, it is presumed that the internalised disorders are under-represented in large scale surveys where the instruments used to measure distress have been in the form of checklists (Luthar & Cicchetti, 2000).

4.2. Relevance of stress to psychosocial models of adaptation:

Despite widespread usage, the term stress is too nebulous to have scientific meaning (Rutter, 1983, in Trad & Greenblatt, 1990, p. 24). Stress may be a physical, emotional, cognitive or chemical factor that exerts significant pressure on an individual's ability to function adaptively (Trad & Greenblatt, 1990), and so it usually demands that the individual makes some adaptation to accommodate the pressure. The adaptation may be adequate or inadequate, with the adequacy being determined by (i) decreased stress levels; (ii) social appropriateness; or (iii) healthier functioning within the individual in either the long or short term (Dawes, 2000). The distinctions between these various forms of adaptation are complex and can be highly problematic. Consider a child who is stressed through living in extreme poverty and perpetual hunger: he may sniff glue to blot out the hunger pangs and thereby decrease his stress levels; he may steal food from neighbours - a response, though not

socially appropriate that would decrease the hunger pangs; or he may have to tolerate hunger pangs and perhaps develop physical and other complications, until he has been 'processed' through various government departments and a social grant has been accessed by his primary caregivers to gain food security. The concept of adaptation raises many ethical and practical issues, especially in terms of its applicability to vulnerable children and the context of HIV/AIDS.

Stress can be understood as either a stimulus, a response or an interaction between stimulus and response:

- It can be a manifest *stimulus event* that necessitates adaptation (Garmezy & Masten, 1990). Some events are regarded as being inherently stressful (such as the death of a parent or being diagnosed with a terminal illness). The risk literature largely adheres to this paradigmatic approach and focusses on the impact of life events or experiences that are considered to be intrinsically stressful.
- It may be regarded as a *syndrome of psychological and physiological responses*, involving neuro-hormonal and psychoneuroimmunological reactions to disequilibrium (Burns & Arnold, 1999). This conception of stress has found acceptance among those who advocate stress management techniques, such as life style adaptations and relaxation training as a means to decrease the recurrence of stress-related conditions and to decrease the suppression of the immune system (Burnette, Koehn, Kenyon-Jump, Hutton & Stark, 1991). HIV/AIDS is a disease of the immune system that is directly affected by stress (Cohen & Herbert, 1996). One of the major principles of "living positively" (once diagnosed HIV+, the procedures that can be adopted to manage the repercussions of the virus and prolong one's life) is to decrease or actively manage stress levels.
- It can be an *interaction* between both stimulus and response, with an intervening *subjective, experiential appraisal*. This perspective recognises that one cognitively assesses an event or situation to evaluate if it is threatening or exceeds one's capacity to cope (Lazarus, 1991; Tomaka, Blascovich, Kibler & Ernst, 1997). If the event is considered to be too demanding, a stress-induced activation of the sympathetic nervous system follows (Nairne, 2000). If the individual perceives it to be within his or her coping capacity, various coping strategies are used. The cognitive appraisal takes place in the 'here and now', taking into consideration the current context. Therefore, a particular stimulus might activate a stress response at one point, a coping strategy at another and minimal response at yet another time. The cognitive appraisal of the interaction of the stimulus determines the response creating variations in

response across time and person (Lazarus, 1991).

The coping literature largely complies with this third mode of conceptualising stress. Coping is thus conceived as a bio-psycho-social interactional model of stress. Coping, from this perspective, adheres to a “goodness-of-fit” model since psychosocial adaptation is regarded as a match between the demands of a situation or event and the capacities, including the cognitive appraisal, of an individual within a specific environmental context (Aldwin, 1994). There is empirical support for the effectiveness of managing stress reactions through altering the cognitive attributions to significantly enhance quality of life (Lazarus, 1991; Nairne, 2000; Smith & Carlson, 1997).

In considering stress as a stimulus, there are various ways in which the nature of stress could be categorised: (i) internal or external in source; (ii) acute or chronic in duration; and (iii) multi-dimensional; and (iv) developmental perspective:

- **External or internal sources:** Stress can be regarded as a stimulus event/s that arises primarily from external or internal sources (Horowitz, 1992; Nairne, 2000). External sources of stress include: (i) *significant life events* that are defined as major events, either positive (securing a good albeit challenging job) or negative (death of a loved one) that are associated with changes in a person’s day-to-day functioning and activities; (ii) *daily hassles* are the regular irritations and difficulties of life (Aldwin, 1994) such as concerns about one’s appearance or health (Nairne, 2000), having to carry heavy buckets of water, collect firewood, stand in long queues, endure unpredictable transport facilities, etc.; or (iii) *environmental factors* that are present in an individual’s environment such as poverty, overcrowding, dust, frequent deaths and bereavement, drought, etc. These external sources of stress are considered to be particularly persistent in the lives of the children within the current research context.

Internal sources of stress include: (i) various aspects of *attributional styles* such as (a) the amount of control that an individual perceives him/herself to have over a situation, such that perceived control over an event is associated with decreased stress (Horowitz, 1992); or (b) the typical explanatory style of an individual: for example, people who make internal, stable and/or global attributions of negative events are more likely to suffer stress-related health problems (Nairne, 2000); or (c) *personality and temperamental characteristics* of the individual: for example, optimism reduces stress; Type A (hard-driving, ambitious, easily

annoyed) personalities have elevated stress levels and increased risk of health problems (Horowitz, 1992); and (iv) *genetic or physical in origin* which takes into account the various stress factors that arise from genetic abnormalities or physical dysfunction or even less than optimal physical functioning.

- **Acute-chronic duration:** Stress could also be categorised along an acute-chronic dimension (Horowitz, 1992; Smith & Carlson, 1997). Acute stressors demand changes in the existing circumstances and a disruption of the status quo. They may be severe in nature, such as sexual abuse or floods, or they could be less severe (for example, a domestic or peer dispute). Chronic stressors are on-going aspects of the internal or external environment that undermine an individual's ability to cope (Compas, Malcarne & Fondacaro, 1988; Horowitz, 1992) and deplete one's physical and emotional resources. Chronic stressors include the predictable stressors and daily hassles that form a persistently adverse theme in one's life: e.g. poverty, discrimination and limited access to resources. In some situations, acute events may become chronic if the individual is unable to cope adaptively or if the stressful events persist over a prolonged period of time (Gibson, Swartz & Sandenbergh, 2002). Neutral stressors fall midway, are less calamitous, more mundane, and even though they create pressure, are not usually associated with maladaptive responses (Trad & Greenblatt, 1990).
- **Multi-dimensional:** The integrated, multi-dimensional model for categorising stressors (Aldwin, 1994) conceptualises stress along three axes: (i) the *duration* of a stressor can be acute or chronic; (ii) the *severity* of a stressor with traumatic stress placed at one extreme and daily hassles are equated to relatively minor stressors at the other end of this axis; (iii) the *cognitive appraisal* of one's own capacity to cope, in combination with various other factors that moderate the impact of a stressor. While Aldwin's (1994) integrated model enhances understanding of the multi-dimensional nature of stress, the *source* of stress is considered to be especially relevant within the current research context, whereas she does not include this as a dimension for consideration. The advantage of this integrative approach is that it takes into account the reality that stressors tend to co-occur and interact with one another, acting additively and synergistically (Aldwin, 1994; Arnold, 1990; Baylis, 2002; Masten, 2001). For example, poverty creates stress through malnutrition, poor environmental circumstances, discrimination, inadequate parenting due to worry and pre-occupation, discouragement and resentment at one's social status (Arnold, 1990).

- **The developmental perspective:** This perspective takes into account children's reactions and the specific vulnerabilities that they face at different stages of development. Arnold (1990) hypothesised that there are developmental feedback loops in which the effects of stress can affect, either beneficially or detrimentally, any of the developmental parameters. In turn, these impact on the child's future ability to tolerate or master stressful circumstances. For example, the impact of a stressful event in early childhood may differ from the impact of the same event on an older child. Young children have the advantage of securing some protection from stressful events by virtue of their lack of understanding of an event in combination with the active role of their primary attachment figures (Trad & Greenblatt, 1990). The meaning that they attribute to the event is unlikely to be well developed and may reflect egocentric thinking (Killian & Perrott, 1994). Older children may not have the advantage of similar buffering effects, but may have benefited from previous life experiences that have assisted adaptive coping (Luthar & Cicchetti, 2000) and they may be better equipped to accurately appraise the nature of a stressful event.

In addition, the epistemological stage theory approach adopted in many theories of child development suggest that children may be exposed to stressors that are unique to their specific psychosocial developmental stage. For example, a child in the psychosocial stage of industry verse inferiority (Erikson, 1963) may not have the opportunities to develop a sense of mastery during this stage of development and so his or her future development may be compromised.

The heterogeneity in models used to conceptualise and categorise stress create difficulties in terms of measuring the degree of stress to which an individual has been exposed. Strategies to measure stress in children have typically relied on parent or educator perceptions of stress, even though it is known that the presumably objective reports of educators and parents do not correlate well with children's own reports of stress (Compas et al., 1988; Connors, Parker, Sitarenios & Epstein, 1998). Adults, for example, regard major life events as a primary source of stress, whereas children are more likely to regard daily hassles as being stressful (Compas et al., 1988; Lazarus & Folkman, 1984; Nairne, 2000; Smith & Carlson, 1997). Nevertheless, child stress inventories are generally modelled on their adult equivalents with a focus on stressful events. Questionnaires list and rank order stressful events in terms of the exposure and/or intensity of various stressors that a child may

have experienced over a given period of time. However, this assessment technique fails to take into account either the child's subjective experience of the stressor (Howard & Dryden, 1999; Smith & Carlson, 1997), or the child's appraisal of the event and his or her perceived ability to cope with the event (Horowitz, 1992; Lazarus & Folkman, 1984). One advantage of this approach is that it is consistent with the risk literature. While some events such as parental death may be regarded as being inherently stressful, the child's appraisal of the situation is of critical importance. For example, even an event as seemingly catastrophic as parental death can give rise to a variety of negative and positive emotions: relief that the parent no longer requires daily HBC and is no longer in pain, pleasure at having more time to play and study, sadness at the parent's death and worry about impending changes in one's own daily life (Killian et al., 2002). Only a limited understanding of a child's experience is gathered by listing the acute and chronic stressors to which s/he has been exposed. This checklist approach needs to be supplemented by considering the child's subjective experience of the stressors.

The vulnerable children who are the subject of this research have probably been exposed to various forms of stress from both external and internal sources, that are acute and chronic in nature and are severe and/or debilitating in impact. The onslaught of difficulties that they and those who form their social support systems have faced may have compromised their cognitive appraisal of these stressors. Given these stressful living circumstances, one can regard the children as vulnerable to developing various emotional and social problems.

4.3. Models of risk and vulnerability

A different paradigm connects psychosocial risk, as opposed to stress, to the onset of psychological and behavioural problems in children. This theoretical model began with the seminal longitudinal studies conducted by Garnezy and Rutter (1983) and Werner and Smith (1982). These studies tracked age-cohorts of children over much of their childhood, adolescence and into adult years. Previous studies that linked psychopathology and adversity had been criticised for being heavily reliant on retrospective constructions of which childhood experiences were the precursors to which forms of psychopathology. In order to overcome this methodological flaw, epidemiological and longitudinal experimental designs were adopted to optimally explore the early precursors of psychosocial problems in children and adults (Masten, 2001; Rolf et al., 1990). By tracking children longitudinally, it was possible to demonstrate that a child whose development was compromised at one point in time, may be developing an adaptational strategy that leaves him or her vulnerable, or

has a steeling effect against future adversity (Jenkins & Keating, 1998; Masten & Coatsworth, 1998). It also became clear that emotional and behavioural problems may be of relatively short duration when considered over the whole developmental spectrum (Masten, 2001; Werner, 1984).

Risk factors are defined as any influence that increases the statistical probability of onset, maintenance or deterioration in a problem condition (Coie, Watt, West, Hawkins, Asarnow, Markman, Ramey, Fraser, 1997; Luthar & Cicchetti, 2002; Rutter, 1999; Shure & Long, 1993). Working primarily within first world contexts, the early studies identified risk factors that increased the likelihood that children would develop various emotional, social and behavioural disorders. Much commonality emerged in the risk factors that were identified: poverty, parental psychiatric disorder, large family size, overcrowding in the home, marital conflict/divorce, poor parenting techniques and parental criminality (Garmezy & Rutter, 1983; Rutter et al., 1975; Werner & Smith, 1982;). Many of these risk factors still have currency 25 years later (Howard & Dryden, 1999). Risk research still principally focusses on identifying environmental factors (the external sources of stress discussed above) that predispose a child to developing psychopathology and other adverse outcomes (Fraser, 1997; Garmezy, 1985; Luthar & Cicchetti, 2002).

It seems that risk factors work cumulatively and synergistically (Baylis, 2002). Rutter (1979) reported that the presence of an isolated adverse factor in a child's life did not increase the probability of disorder, but in the presence of multiple risks, children manifest an increase in behavioural problems. He found that children with one risk factor, even a severe one such as parental death, had the same statistical probability of developing problems as children with no exposure to risks (*ibid.*). Whereas, the presence of two risk factors can lead to a four-fold increase in the probability of adverse outcome and the presence of four or more factors can lead to a ten-fold increase (Luthar & Cicchetti, 2000; Rutter, 1979; Sameroff, Seifer & Bartko, 1997). Confirming these estimates, Jenkins and Keating (1999), using a cross-sectional methodology with children aged six and ten years, found that children who had not been exposed to any risk factors showed an approximately 10% rate of difficult behaviours, compared to the five times higher rate (50%), found amongst children who had been exposed to four or more risk factors. Similarly, Rutter (1985) found that 5% of children with two risks showed serious disorder, compared to 20% of children with four or more risks (Rutter, 1985). Chronic exposure to stress increases the risk of pathology (Masten, 2001), negatively effects a child's ability to manage adversity and decreases their psycho-neurobiological ability to manage stress (Perry, 2001 and Schore, 2001, in Baylis, 2002; Ungar,

2001).

The cumulative impact of risk is worrisome. Many risk factors intrinsically involve the co-occurrence of multiple distressing events, accompanied by extreme daily hassles at several of the systemic levels. This phenomenon is sometimes referred to as clustering of risk (Baylis, 2002). For example, poverty creates cumulative effects of chronic, life-long stress and is known to increase risk exponentially (Barbarin & Richter, 2001b; Brooks-Gunn & Duncan, 1997; Luthar & Cicchetti, 2000; Masten, 2001). In terms of the HIV/AIDS pandemic, being orphaned may predispose a child to stigma and discrimination, loss of educational opportunities and frequent changes in care arrangements with multiple caregivers (see Chapters 2 and 3). However, not all children exposed to multiple risk factors develop problems and some are remarkably resilient (Grotberg, 1999; Masten, 2001) as will be discussed in Chapter 5.

Understanding the mechanisms through which risk factors impact on children's lives has had to take into account resilience processes that seem to strengthen children despite their adverse circumstances (Fraser, 1997). Although confusion still seems to reign, one can conceptualise the effect of risk variables in two broad ways. Firstly, risk factors can be conceived as having direct and causal impact by creating loss of well-being in the child (Rolf et al., 1979; Rutter & Pickles, 1987; Werner, 1993; Werner & Smith, 1982). A simple bivariate statistical model is used for this method of conceptualising risk. Using this model, childhood problems are considered to be highly interrelated and stem from one risk pattern (Jessor, 1993). The pernicious generic risks that are repeatedly identified in the literature create this risk pattern, especially when they co-occur or are especially severe (Garnezy & Rutter, 1983; Rutter et al., 1975; Werner & Smith, 1982). Parental death, poverty and being the victim of child abuse are examples of risks that could apply to this model. There is however a simplicity in the model that does not take into account the various factors that moderate the impact of these risks.

An alternative model holds that childhood problems could be regarded as having both common and unique risk structures (Mrazek & Haggerty, 1994), such that co-occurring sets of conditions need simultaneous consideration. The presence of risk variables, especially if they are numerous or severe in nature, can impact in various ways *depending on* individual, family and contextual conditions. Research has identified various factors that statistically alter the degree of impact for certain groups of children, either in the present or in terms of exposure to future adversity (Arnold, 1990; Fraser,

1997). These variables, that are essentially derived from statistical models of probability, can be described as moderators and mediators.

A moderator is a variable that influences the relationship between two (or more) other variables (Kazdin, 2000). Some sets of circumstances seem to moderate or subdue the impact of risk in the present, while others appear to create a “steeling effect” by enhancing the child’s ability to cope more effectively with adversity at a later developmental stage (Masten, 2001). Gender moderation shows that boys generally report less stress and exhibit more distress behaviourally through antisocial behaviours (Kavanaugh & Hops, 1994). The nature of a child’s attachment to his/her primary caregivers is another important moderating variable. Young children with secure attachments are less likely to be affected by stressful situations, and are more likely to exhibit improved social functioning and be empathic and compassionate (Barton & Zeanah, 1990).

A mediator is the process, mechanism or means through which a variable operates or produces a particular outcome (Kazdin, 2000). For example, physiological and psychological responses to stress can be indirect or mediated through various contextual and other variables (such as age, gender, race and intellectual ability) that affect the degree of impact of specific risks (Fraser, 1997). The impact of risk can be mediated more effectively in boys with routine and clear role definition, whereas for girls, a mediating variable would be the assumption of appropriate responsibilities (Kavanaugh & Hops, 1994). The impact of parental death is mediated by the child having secure attachments with more than one primary caregiver (Christ, 2001; Masten, 2001). It seems that some individual, family and circumstantial conditions mediate risk by deflecting the impact of stress (Arnold, 1990).

It is frequently difficult to differentiate between mediators and moderators, as the other important variables that impact on the overall outcome for children have to do with the concepts of coping and resilience. Ungar (2003) states that one also needs to take into consideration the premorbid level of adaptive functioning so that children who were previously compromised by living in high risk environment are exposed to both acute and chronic stressors such that they can capitulate under the strain, develop good coping and ‘beat the odds’, or there may be an inoculation or invulnerability factor that affects overall outcome. Likewise those children who live in low risk environments may be provided with opportunities for growth, or may fail to develop adequate coping strategies, or may stagnate in their overall level of functioning. Nevertheless, exposure to risk is more associated with adversity.

4.4. Risk factors relevant for children in high prevalence HIV/AIDS communities:

As outlined in Chapters 2 and 3, some of the well-recognised risks are especially likely to be prevalent in vulnerable children living in high prevalent HIV/AIDS communities. Whilst trying to avoid duplication of the material covered previously, the theories associated with these risks will be briefly over viewed.

4.4.1. Poverty

“Poverty has been described as the new face of *apartheid*: millions of people living in wretched conditions side by side with those who enjoy unprecedented prosperity” (UNICEF, 2000a, p. 44). Ten percent of the people in the world possess ninety percent of the world’s wealth. The reasons for the world-wide inequalities are multiple, governed by macro-economic policies (Montgomery & Burr, 2003a) that protect the interests of the wealthy and leave the poorer nations and communities living in the most appalling circumstances of abject poverty and deprivation. Some governments place higher priorities on the welfare of their citizens (countries such as Costa Rica, Panama and Haiti have abolished their armies in order to divert this portion of their budget to poverty alleviation programmes), while others prioritise arms, military and political expenditure, paying only lip service to poverty alleviation programmes. For example, there is a strong relationship between high per capita military expenditure and high infant mortality rates (Montgomery & Burr, 2003a). In an attempt to mainstream children in policy dialogue and encourage a child-centered development strategy (Biersteker & Robinson, 1997), South Africa is the first country in the world to introduce a children’s budget. However, it is an ideal since no money is allocated to this budget, but it provides a forum through which expenditure on children can be tracked, policies modified and strong advocacy with accurate base-line data can be launched. Children in South Africa have yet to reap the benefits of this budget, but it is a step in the right direction. Despite, the impressive improvements in public health, social services and education during the last century, there has been a steep decline in the quality of life for children in the 1980's and 1990's (Fraser, 1997; Haveman & Wolfe, 1994, Proudlock & Rosa, 2003).

Poverty and low socio-economic status play a significant role in determining developmental outcomes (Dodge, Pettit & Bates, 1994; Sampson & Laub, 1994). The Canadian National Longitudinal Study of Children and Youth (Offord & Lipman, 1996) reported an inverse relationship between income adequacy and behavioural problems. Poverty creates its own self-perpetuating downward cycle of disadvantage: decrease in the availability of social and health services; fewer

educational opportunities and resources; higher unemployment rates; increases in child labour and exploitation; and widespread malnutrition (Hunter & Williamson, 2000). Poor people live without fundamental freedom of action and choice, often exposed to discrimination and ill treatment by institutions of the state and society, powerless to influence key decisions affecting their lives (WDR, 2000/2001). These dimensions add impetus to the downward spiral into extreme poverty.

The numerous ramifications of growing up in poverty are well recognised in the literature. It affects children both directly and indirectly (Sherman, 1994). Poverty affects children directly by reducing the quality of food, shelter, health care, education, recreation and transport that a family can afford. Poor children live in less safe and more hostile physical environments. Poverty affects children indirectly by "bringing out the worst in parents who struggle to manage in often impossible circumstances" (Larner & Collins, 1996, p. 72). When they are exhausted from low-paying jobs and debilitated by the sheer demands of coping with inadequate resources, parents simply find it harder to be consistent in discipline, to be sensitive and responsive to children's needs and to provide a range of socially and educationally stimulating experiences (Brooks-Gunn, Klebanov & Duncan, 1997; Duncan, Brooks-Gunn & Klebanov, 1994; Hart & Risley, 1995). McLoyd's (1998) empirical work on children raised in poor homes shows that by age 5, these children have more fears, are unhappier, are more prone to aggressive behaviours, infections and have lower IQ's. The financial difficulties in themselves lead to increased risks of exposing children to the other risks associated with poverty, including mental health and social problems (Richter, 1994). Thus the longer children live in poverty, the more severe the impact (Toomey & Christie, 1990).

Maslow's (1971) hierarchy of needs posits that the most basic human needs are for physical sustenance and shelter, followed by the needs for safety and security, a sense of belonging and love, self esteem and identity and finally self actualisation. For people living in poverty, it is probable that none of these basic needs are met. While this model of human needs had been widely accepted in western countries (and is consistent with human rights advocacy work), there have been serious critiques of the concept of a hierarchy of needs in which one needs must be satisfied before one can adequately contemplate meeting the next set of needs. Applying Maslow's model to people who live in poverty means that poverty-stricken individuals would experience less pressure to meet their needs for love and belonging (and even less so for self esteem and actualisation) while they struggle to meet their basic survival needs.

A fundamentally different view of human needs has been proposed by Max-Neef, a Chilean economist (Fisher, 2003). Max-Neef (1987) believes that the first world's materialistic assumptions about the nature of human beings have directly contributed to increased poverty, massive debt and ecological disasters. He and his colleagues have developed an alternate taxonomy of human needs that focusses on the "satisfaction of fundamental human needs, on the generation of growing levels of self-reliance, and on the construction of organic articulations of people with nature and technology, of global processes with local activity, of the personal with the social, of planning with autonomy, and of civil society with the state" (Max-Neef, 1987, p. 12). In his taxonomy, there is a distinction made between needs and satisfiers. Human needs are few, finite and classifiable (in contradiction to the western view of "wants" that are infinite and insatiable). Needs form an interactive and interrelated system that is constant across culture and history. With the exception of the basic needs for survival and subsistence, there is no hierarchy but rather processes of simultaneity, complementarity and trade-offs (Fisher, 2003). Max-Neef identifies nine fundamental human needs: subsistence, protection, affection, understanding, participation, recreation (leisure, time to reflect and be idle), creation, identity and freedom. Each of these needs can then be classified according to the existential categories of being, having, doing and interacting (See Table 5.1).

Although each culture develops its own ways of satisfying these needs, there are five types of satisfiers (ranked in ascending order according to their ability to promote development): violators/destroyers, pseudosatisfiers, inhibiting satisfiers, singular satisfiers, and synergistic satisfiers. To demonstrate the systemic properties of these needs and satisfiers, consider the example of watching television. This activity may satisfy the need for recreation, but it interferes with the needs for understanding, creativity and identity. Many wealthy individuals are indeed poverty-stricken in terms of having their basic needs for understanding, affection, creation and participation violated in their singular pursuit for material possessions. Likewise many people who live on the brink of having their basic subsistence needs met, have their needs for participation, identity and freedom met.

Synergistic satisfiers lead to the simultaneous satisfaction of more than one need. Examples of synergistic satisfiers include breastfeeding, educational games, family rituals and ceremonies, participatory action research and democratic community development programmes. Max-Neef (1987) claims that a paradigm shift is needed at each of the systemic levels, but especially in terms of global economics, to re-conceptualise human needs and gain insight into the key problems that impede the

Table 4.1: Max-Neef's taxonomy of human needs:

Fundamental human needs	Existential category of human needs			
	Being (Qualities)	Having (Things)	Doing (Actions)	Interacting (Settings)
Subsistence	Physical and mental health	Food, shelter, work	Feed, clothe, rest, work	Living environment, social setting
Protection	Care, adaptability, autonomy	Social security, health systems, work	Co-operate, plan, take care of, help	Social environment, dwelling
Affection	Respect, sense of humour, generosity, sensuality	Friendships, family, relationships with nature	Share, take care of, make love, express emotions	Privacy, intimate spaces of togetherness
Understanding	Critical capacity, curiosity, intuition	Literature, teachers, policies, education	Analyse, study, meditate, investigate	Schools family, universities, communities
Participation	Receptiveness, dedication, sense of humour	Responsibilities, duties, work rights	Co-operate, dissent, express opinions	Associations, parties, churches, neighbourhoods
Leisure	Imagination, tranquillity, spontaneity	Games, parties, peace of mind	Day-dream, remember, relax, have fun	Landscapes, intimate spaces, places to be alone
Creation	Imagination, boldness, inventiveness, curiosity	Abilities, skills, work, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences
Identity	Sense of belonging, self-esteem, consistency	Language, religions, work, customs, values, norms	Get to know oneself, grow, commit oneself	Places one belongs to, everyday settings
Freedom	Autonomy, passion, self-esteem, open mindedness	Equal rights	Dissent, choose, run ricks, develop aware ness	Anywhere

actualisation of fundamental human needs in society, community and family. This becomes possible when satisfiers are not perceived as economic goods, but rather as forms of organisations, political structures, social practices, subjective conditions, values and norms, spaces, contexts, types of behaviour and attitudes. Most effective community developmental organisations incorporate this paradigm into their work, by reformulating the fundamental human needs and their satisfiers. Max-

Neef's (1987) model acknowledges the universal need for food security but sees that the form of society defines the way in which people go about satisfying this and other needs. For example, people from consumerist, communal, aesthetic societies all still have the same basic needs but have different methods of satisfying these needs. When people acknowledge that they can critically reflect on how to satisfy their needs, the other basic needs must be taken into consideration for people to feel satisfied and fulfilled. Poverty stricken and wealthy people have the same needs for participation, acceptance, understanding and so forth. Acknowledging this similarity, allows one to go forward towards a more ecologically viable and sound way of living. This may significantly reduce the risks that have been regarded as inherently the lot of poverty stricken individuals.

4.4.2. Lack of secure attachment to a primary care-giver

The quality of the relationship between a child and its primary caregivers is a well-documented predictor of outcome for children's psychosocial functioning (Rutter, 1994; Shaffer, 2002). Those children who develop secure attachments are likely to exhibit improved social functioning, greater empathy and higher self esteem, while those with insecure attachment relationships are likely to manifest a variety of negative interactive patterns with family members, peers, and teachers (Sroufe, 1997). Barton and Zeanah (1990) note that insecure maternal attachments were over-represented in clinical samples, whereas there were almost no children who were securely attached in child clinical samples. Similarly, children raised in homes with a psychiatrically disordered parent were more likely to develop psychosocial problems if the home was characterised by high levels of conflict and if the child did not enjoy a supportive relationship with at least one parent/adult (Rutter, 1994). The universality of these findings leads to the conclusion that having a secure, supportive relationship with at least one person is both a significant moderator and mediator of the impact of stressful life events on children (Masten, 2001).

The availability of attachment figures is especially important in young children. The young child has an immediate and all-purpose response to stress - s/he seeks immediate contact with the attachment figure (Macoby, 1983, in Barton & Zeanah, 1990, p. 211). If the parent is unavailable to the child for reasons of sickness, death, pre-occupation with own stressors or life difficulties, the consequences for the child are formidable, unless such unavailability is compensated by the presence of a primary caregiver with whom the child has or can develop a secure relationship. The extended family has traditionally been the source of alternate primary caregivers, but as the HIV/AIDS onslaught continues, it may be necessary for community members to make themselves available to

children as caring, consistent and supportive adults so as to mediate the impact of the stressor inherent to those affected by the pandemic.

4.4.3. Exposure to political violence and discrimination:

The partnering communities have political violence as an integral part of the history of their area. The violence aimed to disrupt the entire fabric of social, economic and community relations to create a fragmented and disempowered society (Higson-Smith & Killian, 2000; Machel, 2001). Destruction of communities through instilling terror, humiliation and degradation on ordinary citizens has major adverse consequences for children. Although the advent of democracy in South Africa in 1994, led to a decrease in political violence, many children still live with factional conflict in a situation that has yet to be stabilised (Lachman et al., 2002). In addition, chronic political violence results in general increases of all forms of violence, including domestic, sexual and criminal violence (Reeler, 1994).

Ten to twenty percent of children exposed to political violence are likely to develop psychiatric symptoms such as severe manifestations of anxiety, depression, post traumatic stress disorders, emotional and conduct disorders (Dawes, 1994; Magwaza, Killian, Petersen & Pillay, 1993; Paeans, 1994; Terr, 1990). When children grow up without protective parents, observing parental humiliation, they could develop distorted family relations, revenge fantasies and possibly disrupted moral development (Lachman et al., 2002). Under normal circumstances, children grow up with a belief that their parents are strong, powerful and able to protect them. When children grow up witnessing powerlessness, helplessness and humiliation, the traditional family hierarchical subsystems and the belief in parental omnipotence is seriously undermined. For patriarchal communities, such as Zulu society, respect for elders is an important cultural value that could be eroded. While many of the children in the current study were not yet born at the time of South Africa's first democratic election in 1994, their parents would have experienced conditions during their own childhoods that were far from optimal. In turn, this may create cross-generational emotional and social problems. Those individuals who themselves experienced secure attachments during childhood are the one most likely to be able to develop secure attachment and offer effective parenting to their children.

In psychodynamic terms, experiencing one's parent as lacking the ability to protect one, has been linked to the origins of aggression, shame and the desire for revenge (Gay, 1988). Revenge is an

integral aspect of organised violence, where individuals, families, groups and communities seek collective retaliation and vengeance following acts perpetrated against them, their kith and kin. Children may actively fantasise about ways in which they can seek retaliation and punish the perpetrators (Killian, Meintjes & Nhlengetwa, 2001; Machel, 2001). This may also be consistent with the collectivist nature of societies in which the group is more significant than the individual. Furthermore, children may desperately want to compensate for loss and humiliation of their parents, particularly if it is the mother who has been threatened (Punamäki, 1989; 2000). The child may then engage in “saviour” daydreams that could lead a child adopting heroic roles by becoming actively involved in the struggle with the objective of restoring family and national identity.

Unless HIV/AIDS is de-stigmatised, there is a risk of similar psychodynamic responses developing in children who observe their parent’s suffering with an illness that they perceive to have been inflicted by someone else - a sexual partner, non-supportive government facilities, and so on. The cognitive appraisal of a stressful event is critical in defining how the individual copes with the event (Lazarus, 1993) so that children’s understanding of HIV/AIDS needs to be an enlightened and compassionate one.

4.4.4. Children’s understanding of illness and death

The psychosocial impact of chronic terminal illness in children is relevant to this dissertation, especially for those children who are HIV+. Kubler-Ross (1983) asserts that terminally ill and dying children mature more quickly through their powerful experiential and environmental learning. Dying children not only understand that they are dying but also develop mature concepts of illness and death (ibid.). Although the cross-cultural applicability of this theory has not yet been ascertained, it may be relevant in dealing with the psychosocial needs of children who are terminally-ill with an AIDS-related condition or who are witnessing the death of loved ones.

The acquisition of any concept is attributable to a variety of developmental and contextual variables such as biological readiness/maturation, life experiences, intelligence, family attitudes and values (Orbach, Gross, Blaubman & Berman, 1986). A mature concept of death can be considered to incorporate three essential elements: (i) irreversibility - an awareness that once someone is dead, they are not going to come back to life; (ii) non-functionality - an understanding that all life defining functions have stopped, e.g. the heart no longer beats and the person can no longer feel pain; and (iii) universality - an awareness that everyone will die and that it is not only the old who die (Ayyash-

Abdo, 2001; Speece & Brent, 1984). The understanding of universality that most cultures implicitly hold concepts of "good death" where the deceased is old or has been suffering for a long time and "bad death" where it is unexpected, self-inflicted and/or the deceased is young. AIDS related deaths are usually regarded as "bad deaths", and much money will be spent on trying to cure a terminally ill person and ward off the pending "bad death" (Marcus, 2002).

Little is known about the way in which children acquire an understanding of illness and death in the midst of a pandemic. Logically emotional and experiential factors would be critical in the child's understanding of these concepts, as well as in determining the degree of sophistication of a child's view of illness and death. Previous experiences of serious illness and death facilitates a better understanding of all aspects of illness and death and a different order of acquisition of the concepts (Ayyash-Abdo, 2001; Orbach, Gross, Blaubman & Berman, 1986; Kane, 1979). There are also a number of social and contextual variables that are likely to significantly impact on the way in which children understand illness and death. Methodological variations in the studies on the acquisition of the illness and death concept have contributed to some of theoretical diversity: some have used healthy children as their subjects (Kane, 1979; Kastenbaum, 1972; Anthony, 1940), whilst others have considered the experience of the dying child's awareness of death (Kubler-Ross, 1983).

There are various theoretical schools that have attempted to understand how children developmentally grasp the concepts of illness, death and dying. Perhaps those that confine themselves to description are the most relevant in the current research context. Anthony's (1940, in Aldwin, 1994) classic studies on British children found that children frequently think about death. He identified five stages in the process of understanding death, with the most pivotal stage occurring at around 7 or 8 years. The child moves from apparent ignorance to a clear and logical grasp of biologically essential terms of death. Using child subjects who had considerable experience of death and the horrors of war, Nagy (1948, in Aldwin, 1994) identified three stages in the development of the death concept: (i) the *separation stage* (3 - 5 year olds) when the child is capable only of grasping that a significant person is separated from them and such separation is presumed to be temporary in nature - they look or wait for the deceased; (ii) the *personification stage* (5-9 years) is marked by the child assigning the qualities of a person/spirit to death and perceives it as something that should not be happening - 'someone' comes, often in an aggressive way, and takes away the deceased; and (iii) a realisation that death is *universal, inevitable and is a lawful process* (age 9 years onwards). Kubler-Ross (1983) contends that terminally ill and dying children grow up and mature more quickly

through their powerful experiential and environmental learning. Dying children not only understand that they are dying but also develop a mature concept of death at a more rapid rate to those children who have little exposure to terminal illness and death.

Studying children suffering with leukaemia, Bluebond-Langner (1978, in Killian & Perrott, 1994) distinguished five successive stages in the acquisition of disease information, with concomitant changes in the self concept: (i) The child realises that s/he has a serious illness and his/her self concept accommodates the notion of being seriously ill. (ii) The child begins to be aware of the drugs and side effects and the self concept responds by acknowledging the serious illness although s/he maintains a belief that s/he will get better. (iii) The child begins to understand the purpose of treatments and procedures and accepts that s/he will always be ill, but there will be times when s/he will feel better. (iv) Gradually the child becomes aware that the disease consists of a series of relapses and remissions but /he denies the terminal nature of the illness. The self concept incorporates the idea that s/he will always be ill and will never get better. (v) In the final stage, the child is able to acknowledge that death is probable and the self concept adjusts to the reality that s/he is dying. Progression through these stages is dependent upon significant cumulative events occurring throughout the course of the illness. In HIV+ children, stages two and three may not be possible in the absence of treatment regimens being available for the vast majority of sufferers. It seems that the role of experience is more pertinent to the child's understanding than age or intellectual ability. For example, 3 and 4 year old terminally ill children knew more about illness than very intelligent nine year olds. Thus, experiential learning is a significant factor for terminally ill children. It is significant that children seem to acquire much of their information about the nature of their illness indirectly by observing the subtle changes in their significant caregivers' reactions after the diagnosis and prognosis had been given and eventually accepted (Black, 1996; Wachter, 1979, in Stillion & Wass, 1979). The significance of experiential learning may be especially detrimental since the prognosis is bleak and treatment unavailable. Children observe their family members' profound suffering, physical deterioration and eventual death. The impact of this observational learning may need serious consideration in terms of media campaigns, government health policies and the families own cognitive framing of HIV/AIDS.

Children's understanding of and ability to cope with illness and death seems to be mediated by cognitive factors (Christ, 2001; Dowdney, 2000; Killian & Perrott, 1994). The cognitive theorists argue that complex interrelationships between disease, personal, familial, social and medical

variables (Shute & Paton, 1992; O'Dougherty & Brown, 1990) are predicated on the child's perception of and response to illness and death (Lazarus & Launier, 1978; Moos & Tsu, 1977). For example, Piaget's theory of cognitive development has been used as a basis for understanding the developmental sequence of the child's understanding of illness and death (Killian & Perrott, 1994). Among the axiomatic principles of Piaget's theory is the belief that children are active scientists who set out to develop an understanding of their world in sequential stages, each stage being qualitatively different from the previous one (Shaffer, 2002). During the first stage, there is no conscious thought and limited language, so the child in this sensorimotor stage knows and discovers through doing. The pre-operational stage (2- 7 years) is characterised by (i) egocentric thinking in which the child is capable of seeing his/her own perspective and is not able to consider another's perspective; (ii) magical thinking in which fact and fantasy are blurred and the child may believe that they can cause something to happen just by thinking about it.; and (iii) over-generalisation -if one person becomes ill or dies, then others will soon follow this same pattern and die (O'Dougherty & Brown, 1990). During the concrete operational stage (7-12 years), children develop the capacity for deductive reasoning and are able to 'decentre' i.e. simultaneously focus on and understand, the relation between several attributes of an object or event. The formal operational stage extends from adolescence into adulthood. It is at this stage that the individual becomes capable of inductive reasoning and abstract thought.

Working from within the Piagetian cognitive framework, Bibace and Walsh (1980) describe the developmental acquisition of understanding the aetiology of illness and disease. Killian and Perrott (1994) found support for this theory when they worked with a sample of hospitalised Zulu children. At the pre-operational stage children have a rudimentary understanding of body parts (O'Dougherty & Brown, 1990) and understand illness in terms of *phenomenism* - they attribute the cause of illness to be an external concrete phenomenon that may co-occur with the illness, but which is spatially and/or temporally remote (Killian & Perrott, 1994); and *contagion* - the cause of illness is located in objects or people that are proximate to, but not touching the child, an example of magical thinking (Bibace & Walsh, 1980, p. 36). The combination of ego-centric and magical thinking combined with over-generalisations, makes children in the pre-operational stage of cognitive development are particularly vulnerable to feelings of guilt for having 'caused' a death to occur (Killian & Perrott, 1994) and are especially fearful of subsequent deaths of significant attachment figures in their lives. Their conceptualisation of illness and the death may make them especially clingy and dependent, anxious and guilt-ridden.

At the concrete operational stage, children attribute the aetiology of illness to *contamination* in which they consider an external person, object or action that was harmful to, or bad for, the body (O'Dougherty & Brown, 1990), or *internalisation* that occurs when the child realises that the cause of illness is either an external contaminant that was internalised (through breathing or ingestion), or an unhealthy internal state such as old age or high blood pressure (Bibace & Walsh, 1980). At the stage of formal operations, the child's rapid cognitive advances facilitate an understanding of illness, the body and body systems (Crider, 1981, in O'Dougherty & Brown, 1990). Adolescents come to realise that illness is triggered by internal bodily dysfunction. They begin to differentiate between various aetiological factors, speculating and hypothesising about cause-and-effect relationships (O'Dougherty & Brown, 1990, p. 243). Therefore, illness is perceived to be caused by external events, but the source and nature of the illness lies in specific internal structures and functions. Psychophysiological explanations are considered to represent the most mature explanations of illness as the child is now able to describe an illness in terms of internal physiological processes and also suggest that thoughts and feelings can affect bodily functioning and be related to the onset of illness (Bibace & Walsh, 1980).

These western theories are based on the assumption of opportunities to acquire both formal and informal knowledge about illness and death. For example, adolescents who attend biology classes are likely to develop more mature concepts of illness and death. When one experiences a linear process of symptoms, diagnosis, treatment, amelioration of symptoms, one internalises the meaning of medical intervention (Saler & Skolnick, 1992; Siegel & Gorey, 1994; Siegel, Mesagno, Karus, Christ, Banks & Moynihan, 1992). In the absence of these opportunities an entirely different process may occur in terms of children's understanding of illness and death.

4.4.5. Child abuse:

The high prevalence of child abuse and neglect among young children in southern Africa has been well established, with child sexual abuse being especially prevalent (Salole, 2004). Child abuse and neglect can take many forms and includes physical, emotional, institutional and sexual abuse, as well as neglect and abandonment. Child abuse and neglect encompasses both acts of *commission* where an individual inflicts harm to a child, and acts of *omission* where an individual fails to take action to protect a child from the likelihood of harm. The phenomenon of child abuse and neglect occurs across all strata of society, however it is especially prevalent in situations of high stress, poverty, unemployment and overcrowding (Lachman et al., 2000). There is little doubt that the most

frequently reported form of child abuse and neglect that was encountered within the partnering communities in this research was child sexual abuse. It is the researcher's opinion however that physical abuse of children occurs frequently under the guise of discipline, with most communities favouring corporal punishment as their disciplinary technique of choice. In addition neglect of children was under most probably under-reported although it was probably a frequently occurring phenomenon

Sgroi (1982) has provided one of the most useful definitions of child sexual abuse. She defines child sexual abuse as a sexual act imposed on a child who is still developing emotionally physically and cognitively. The adult or adolescent perpetrator lures the child into the sexual activity on the basis of their powerful and dominant position over the child's subordinate and dependent status, such that it is the implicit or coercive authority and power of the perpetrator that ensures the child's compliance. Thus, child sexual abuse can be considered to reflect highly gendered power relationships (Levett, 2004) in which children, and girl children in particular, have a lower status and worth than men. Sadly the most prevalent form of child sexual abuse is incest, with extra-familial abuse occurring less frequently.

Some reports suggest that there has been a recent increase in the sexual abuse of children, while other report maintain that there is simply an increase in the number of cases that are brought to the attention of the helping professions. Whichever position one adopts in terms of these arguments, most accept that the abuse of children is fundamentally wrong and unacceptable. It is clear that the high levels of child abuse and child sexual abuse are a major indictment against a country's ability to protect the rights and integrity of its children.

Many victims of child sexual abuse experience their first incident of abuse while they are still pre-pubescent. The research suggests that the average age at which child sexual abuse is likely to commence is at about the age of 11 years (Townsend & Dawes, 2004). However, van Niekerk, (2004) states that Childline has witnessed a steady decrease in the age of child sexual abuse victims, with 50% of children attending therapy services in KwaZulu-Natal, South Africa, being under the age of seven years.

The classic work by Belsky (1980, in Killian & Brakarsh, 2004) applied the systemic model of Bronfenbrenner (1979) to develop an ecological integrated model of child abuse and neglect. He

identified four interactive and interdependent systems that are ecologically nested within one another: (i) ontogenic development, which includes the childhood histories and poor or abusive parenting in the perpetrators of abuse; (ii) the microsystem which takes into account the abused child, the parental, sibling and spousal relationships; (iii) the exosystem which comprises the neighbourhood, community, social support systems and the parent's world of work; and (iv) the macrosystem which encompasses the larger socio-economic, political and ideological variables. From an aetiological perspective, the work of Garbarino, Dubrow, Kostelny and Pardo (1992) has shown that it is the exosystemic variables that are significant in predicting the rates and trends of child maltreatment.

The consequences of child sexual abuse (CSA) on the child victim's social and psychological functioning can be extreme. Assessment of the child victims of abuse consistently report debilitating fears, anxiety, regressive behaviours, nightmares, withdrawn behaviour, depression, anger and hostility, self-injurious behaviours, low self esteem, and inappropriate sexual behaviour (Kendall-Tackett, Williams and Finkelhor, 1993; Browne and Finkelhor, 1986). The meta-analysis conducted by Kendall-Tackett et al. (1993) suggested that there are two common patterns of psychological response: one which is associated with PTSD symptomatology and the other with an increase in sexualised behaviours. Long term sequelae of CSA may include depressive and anxiety disorders, psychiatric hospitalisations, substance abuse, suicidal behaviour, borderline personality disorder, somatisation disorder, eroticisation, learning difficulties, PTSD, dissociative and conversion reactions, revictimisation, poor parenting and an increased likelihood of becoming a perpetrator (Schetky, 1990). A significant percentage of psychiatric patients have been found to have a history of childhood abuse (Bryer, Nelson, Miller & Krol, 1987) with both empirical and clinical studies indicating that childhood physical and sexual abuse is more common among adults who develop major mental illness than previously suspected (Ibid.). It is clear therefore that CSA victims carry intrapsychic scars, with symptoms persisting over many years and into adult life.

The degree of impact of CSA needs to be understood in terms of the parameters of abuse: the frequency of abuse; the duration of the abusive relationship; the relationship of the perpetrator to the child; the type of sexual act; whether or not force was used; the age of the child at the onset of abuse; the age of the offender; whether or not the abuse was disclosed; and the parents' reaction to the disclosure (Schetky, 1990; Browne and Finkelhor, 1986). Single events, whilst being extremely distressing, are not likely to produce effects as powerful as those caused by repeated abuse within

the context of a relationship in which the CSA is evidence of a betrayal of trust. Levett (1989) argues that individual circumstances need to be considered in order to understand the degree of impact on the child. These include the child's circumstances and her range of subjective responses, both at the time of these experiences and later, in retrospect (Myburgh, 1997). A wide range of emotions need to be considered, including possible feelings of warmth and affection towards the perpetrator. Complex, contradictory, or paradoxical feelings often result from abuse experiences. However, the negative consequences attributed to CSA may not in fact be due to the abuse *per se* but due to an accumulation of variables and the interaction of various other factors, such as family dysfunction.

4.5. Summary and critique of the risk and stress related literature

These empirical studies of risk still beg certain questions about the underlying mechanisms through which risk factors impact on children's lives. Given the fact that children with single risks are generally at minimal risk of developing emotional and behavioural problems, whereas there is an exponential increase in pathology with four or more risk factors, the literature still needs to explore the following questions:

- Are there mechanisms through which multiple risks lead to increased rates of disturbance? Or are these simply cumulative in nature? For instance, if a child is exposed to several risk factors is his/her probability of disorder increased cumulatively, or are there other factors such as the nature, duration and presence of other factors that may mediate or moderate the impact of risk factors.
- Are there levels of risk above which most children show disorder, no matter the contextual and environmental conditions in which the child lives? If this is the case, then the implications for effective interventions would need to be carefully evaluated in terms of the goals of intervention. Would one be engaging in treatment of pathology, risk management, amelioration of risk or risk reduction? Would one be trying to enhance general levels of psychosocial well-being or merely work aim to work preventively?
- Why do many children who are exposed to multiple risks, demonstrate resilience and appear to be problem-free despite high levels of adversity? For example, parental death and poverty are widely accepted as major risk factors, but not all children exposed simultaneously to these risks and other major risks develop problems.
- Related to this are questions specific to the HIV/AIDS pandemic. For example, does the experience of numerous deaths of loved ones have an ameliorating or aggravating effect on

peoples' grieving? Can one reasonably hope to generate optimism, hope and faith in children who live in wretched circumstances? Or should all resources and interventions be geared towards reducing environmental risk circumstances? With poverty being acknowledged as the most debilitating risk to which children can be exposed (Aber et al., 1997; Brooks-Gunn & Duncan, 1997; McLoyd, 1998), should poverty alleviation take priority over all other forms of intervention, such as those aimed at offering psychosocial support? However, poverty alleviation programmes do very little to address psychosocial needs of children and it is known that children who have food but no love, do not prosper (Jareg, 2003).

There are no simple answers to these questions. However, sensitivity is essential. One needs to be aware of the critiques that have been raised about the risk literature. Despite the strong empirical support, much of the risk literature can be considered to be somewhat problematic for several reasons:

- *Problem/deficit focus:* The risk models focus on the problems and difficulties that children experience. There is an assumption that certain children are deficient since they lack the internal and/or environmental conditions required for adaptive functioning. Alternatively, through their repeated exposure to adversity their development has been compromised (Howard & Dryden, 1999). Either way, they are assumed to be deficient and beset with problems and difficulties (Fraser, 1997). Equating risk, deficit and problems can have serious consequences, such that all children who have been exposed to certain risks (orphans, poor children or abused children) are considered to be 'problems'. The risk models have tended to largely identify children who belong to minority cultures (Goodlad & Keating, 1990, in Howard & Dryden, 1999), due to their greater risk of exposure to four or more of the generic risk factors (Rutter, 1994). Furthermore, within school and community contexts, the focus has primarily been on identifying problem children - those who exhibit difficult or antisocial conduct (externalised distress). The quite, withdrawn children who do not present management problems (Fleming, Mullen & Bammer, 1997) are less likely to be identified but may be at greater risk of difficulties by virtue of their internalising their problems.
- *Impact of labeling:* The underlying assumption that drives the identification of risk factors is their possible application in predicting future outcomes using statistical probability models (Fraser, 1997), so that one could target high risk children for early preventive intervention (Luthar & Cicchetti, 2002). There is an implicit assumption that the absence of risk factors would lead one to the reasonable conclusion that children who have had few adversities are

at 'low risk' for developing emotional or behavioural problems (Jenkins & Keating, 1999). These assumptions create ideological and ethical tensions. As in all probability models, linear prediction in terms of prognosis is implausible. Therefore, an intervention that labels and targets high risk children may be counterproductive in terms of the ethical analysis of cost and benefit (Steere, 1987).

- *Implications of labeling:* Categorising young children as being at risk, at an early stage of their development, could constitute a risk in itself. It potentially has the effect of lowering teacher expectations of that child's capacity (Soodak & Podell, 1994) and stigmatising them (Toomey & Christie, 1990). A more ethical approach would be to describe some children as experiencing especially arduous and troublesome lives with numerous hardships, making it difficult for them to grow to their potential.

A corollary to the risk model would be a firm belief that children can only exhibit their strengths, talents, uniqueness and special gifts in a facilitative, emotionally-supportive environment (Baylis, 2002). Resilience studies, off-springs from the risk literature, have focused on identifying strengths and assets in individuals and systems that enable people to overcome adversity and grow to their full potential. These will be discussed in the next chapter.

Chapter 5

Theories of Resilience and Strength

An interesting, and unexpected, finding emerged from the risk-related epidemiological studies: some children are able to withstand very high levels of disadvantage without their functioning being impaired and without manifesting either emotional or behavioural problems (Luther & Cicchetti, 2000; Werner, 1995). This discovery gave rise to new research endeavours that identified those factors that appear to help both adults and children to withstand adversity and develop positive patterns of coping (Masten et al., 1990; Rolf et al., 1990; Rutter, 1985; Stouthamer-Loeber, Loeber & Farrington, 1993; Werner, 1993). Thus, the earliest resilience studies involved children who were statistically considered to be at risk of developing psychopathology and other negative outcomes, but appeared to remain unscathed by the misfortunes that they had experienced (Anthony, 1987; Bernard, 1999; Garmezy, 1993; Werner & Smith, 1982). The study of resilience therefore aims to understand the inter-related processes of risk and resilience, to discover why some children grow up to be well-adapted, healthy and productive adults despite having experienced physical, emotional, and/or social hardships. As such, resilience relates to both the stress and risk paradigms that were discussed in the previous chapter and adds a whole new dimension to our understanding of the developmental process.

Resilience is considered to be one of the great puzzles of human nature (Coutu, 2002, p. 46) and ordinary magic (Masten, 2002). These dichotomous positions are reflected in the way in which the study of resilience oscillates between various definitions, models and intervention policies that struggle to explain the various empirical findings. There is an inherent puzzle as to why resilient children do well in life and have the ability to bounce back and cope well despite having experienced profound problems (Masten et al., 1990; Rutter, 1985). They seem vulnerable but invincible (Werner & Smith, 1982). They rise above adversity to work well, play well, love well and expect well (Garmezy, 1986). In fact, research shows that 50% to 66% of children growing up in circumstances of multiple risk (such as endemic poverty, the chaos of war-torn communities, with mentally-ill, alcoholic, abusive or criminal parents) appear to overcome the statistical odds and turn a life trajectory of risk into one that manifests resilience (Dawes, 2000; Masten, 2001; Bernard, 1999). In addition, there is a clear developmental component in that children vary in the degree of resilience that have at different points in their lives. These variations in resilience seem to reflect the interaction and accumulation of individual and environmental risk factors (Howard & Dryden,

1999; Sameroff & Seifer, 1987, in Rolf et al., 1990), once again indicating that a systemic perspective on the social ecology of childhood is required.

5.1. Issues of definition and function:

Resilience may be defined as the process of, or capacity for, successful adaptation despite challenging or even extremely threatening circumstances (Masten et al., 1990; Rutter, 1985). These aspects of the definition have created confusion about whether resilience is:- (i) an *outcome* for children who experience difficulties and still do well in life; (ii) a *skill or capacity* to be robust under conditions of enormous stress and change (Coutu, 2002), perhaps combined with the ability to access social support; (iii) a process of *adaptive coping*, or (iv) a *set of person and environmental variables* that may be specific to particular developmental stages and the contextual circumstances (Richter et al., 1994).

The definitional aspects also raise questions of chronology, in terms of when resilience operates or kicks-in. Does resilience: (i) *pre-exist adversity*: protective processes may function in some children before, during and after exposure to distressing circumstances, such that they begin at an advantage over others as they have an enhanced ability to function optimally despite adversity; (ii) come into being *at the time of adversity* and as such could be considered to be coping strategies that emerge as a result of the difficulty (Smith & Carlson, 1997); or (iii) *begin to function once risk is established*, when they serve to decrease the likelihood of developing problems (Rolf et al., 1990). Kirby and Fraser (1997) have metaphorically compared this last-mentioned form of protective process to immunisation: receiving an inoculation does not enhance health, but provides protection when exposed to the pathogens associated with that specific immunisation.

There is little doubt that much theoretical refinement still needs to be undertaken in terms of clarifying these points about the nature and chronology of resilience. From an applied perspective, all these forms of resilience enhancing processes have the potential to guide and inform interventions and so will be discussed in this chapter.

Various principles have consistently been identified as fundamental to understanding how resilience, in the form of protective processes, function: (i) The *child plays an active role* in negotiating risk situations and overcoming adversities (Rutter, 1999), with the child's cognitive appraisal of a situation being a major predictor of outcome (Aldwin, 1994; Horowitz, 1992; Werner & Smith, 1982). (ii) Protective processes, like risk factors, seem to have an *accumulative impact* - success in

one area of a child's life can serve as a springboard for success in other areas (Brooks, 1998; Masten, 1994; Erikson, 1963), and vice versa. (iii) Certain protective mechanisms are especially important as they create the foundation upon which resilience is built. In children, these include secure attachments, availability of good role models and access to social support (Masten, 2000; Luthar & Zigler, 1992). In adults, the three critical components of resilience seem to be a staunch acceptance of reality; a deep belief, often buttressed by strongly held [religious] beliefs, that life is meaningful; and an uncanny ability to improvise (Coutu, 2002, p. 48). (iv) Certain protective processes are linked to cognitive, emotional or social maturity, as they only come into operation as the child matures (Elder, 1995; Aber et al., 1997).

5.2. Models of resilience:

Various models to conceptualise resilience have been advocated. These models partially reflect the evolution of theoretical development, and each carries intrinsic value and applicability in terms of enhancing the understanding of the concept in terms of their usefulness in guiding intervention programmes:

- *The opposite of risk model* (Rutter, 1987) was the first model of resilience. The early resiliency studies simply assumed that risk and resilience represent opposite ends of a single dimension. At times, these assumptions hold empirical weight. For example, having a poor parent-child relationship is a risk factor, and having a good parent-child relationship contributes to resilience (Baylis, 2002; DeFrain, 1999; Luthar & Cicchetti, 2000; Masten et al., 1990; Rutter, 1985). However, there were sufficient exceptions to this simple model to require the development of different ways of understanding the concept. So it seems that although in certain respects resilience is the opposite of risk, this does not provide a sufficiently comprehensive model.
- The *universal strengths model* was developed during the work of the International Resilience Project (Grotberg, 1995). This model maintains that resilience is an ordinary magic (Masten, 2002): an ubiquitous human capacity that enables a person, group or community to deal with adversity by preventing, facing, minimising, overcoming, and perhaps even being strengthened or transformed, by adversity. We are all naturally endowed with the ability to cope with adversities, but this capacity needs nurturing and support within the context of a facilitative environment to enable resilience to win over vulnerability and risk. In many respects, the universal strengths model is consistent with Bronfenbrenner's focus on contextual systems that can either support or diminish optimal functioning (1986b).

This model has decided appeal. However, it also lacks some empirical validity. Firstly, it seems that 33% to 50% of children do not have the capacity to bounce back after adversity (Masten, 2001). Secondly, there are individual variations in the degree of resilience in different children, at different points in time and in different contexts (Howard & Dryden, 1999; Rutter, 1994). Nevertheless, the shift of focus away from individual deficits onto individual strengths, competencies and capacities was a critical step in understanding the concept of resilience within the context of the individual, family and larger social environment (Brooks, 1994; Gore & Eckenrode, 1994; Masten, 2002; Silberberg, 2001; Ungar, 2003; Walsh, 1998).

One of the most significant contributions in this regard comes from Grotberg (1999) who challenges the use of the term protective factors and calls for a paradigm shift away from the earlier, medically-based, deficit-focussed models of resilience. Through the application of the medical model to the social environment, researchers had focussed on deficits and problems that required diagnosis and treatment. The paradigm shift to *strengths based models* shifted the focus onto building individual, family and community strengths. Grotberg also challenged the notion that people could be 'vulnerable but invincible,' as she believes that people do not remain unscathed by adversity. She contends that resilient people are not protected against, but are better prepared for, difficulties and hardship (ibid.). They address adversity more successfully than non-resilient people: a resilient person grieves the death of a loved one; a rape survivor chooses to go on the long slow road to recovery; the terminally ill address their fears and worries (ibid, p. 6). These were important contributions towards theory building. However, a universal strengths based model does not fully take into account the individual and time variables nor the empirical evidence. It is, however, extremely useful in focussing attention on competencies and contextual variables that can promote or reduce resilience.

- A third model of resilience focusses on the principle that certain children, families and communities have *protective capacities or processes* that enable them to cope better with the trials and tribulations of life. Protective processes encompass a breadth of experiences and mechanisms that enable positive adaptation despite adversity (Baylis, 2002; Luthar & Cicchetti, 2000; Masten, 2002). Protective processes, like risk factors, include dispositional and intrapsychic variables, as well as external processes within the family, school or community environment (Baylis, 2002; Benard & Marshall, 1997; Olson & DeFrain, 2000). Empirical validity for this model is confirmed in that certain universal protective processes

appear to transcend ethnic, social class, geographical and historical boundaries (Howard & Dryden, 1999; Ungar, 2003; Rolf et al., 1990). It seems that protective processes have the power to moderate, mediate or generate adaptive response to risk situations (Rutter, 1987). Identifying those processes that build and boost resilience in at-risk children logically leads to these being incorporated into intervention programmes as specific objectives or focus areas. Likewise, they can enhance attempts to build resilience in all children as they would logically form the basis for educational, life skills and parenting courses and programmes (APA, 2003; Henson, 2004; Silberberg, 2001).

Interdisciplinary research has confirmed the role of three inter-related and interdependent domains of protective processes or influences: (i) internal personal strengths that function as individual assets and resources that include personality and temperamental variables (Benard & Marshall, 1997; Richter et al., 1994); (ii) interpersonal skills that promote the development of internal personal strengths and social skills (Grotberg, 1995; Mallman, 2002) and are useful in eliciting social support; and (iii) the emotional climate, supports and resources within the family and the broader community context (Brooks, 1994; Gore & Eckenrode, 1994; Henson, 2004; Smith & Carlson, 1997). In fact, there is a growing world literature that reflects much consistency in those features that make a difference in the lives of children whose development is threatened by adversity (Masten, 2000). Table 5.1 lists the most frequently reported protective processes (Cowen, 2000; Luthar & Cicchetti, 2000; Masten, 2002; Masten, 2000; Masten & Coatsworth, 1998).

The theoretical position that will be adopted in this dissertation represents an amalgam of the above three models since it is believed that each is useful in guiding intervention. Masten (2002) argues that total risk prevention is ideal but not feasible; risk-activated protective factors are analogous to the crisis intervention models that do little for long term adaptation. This leaves one in the position of trying to straddle different models by targeting the sources of risks, building assets at the individual, family and community level, and at the same time attempting to restore, engage or mobilise the power of human adaptational systems for children (Masten, 2002, p. 13). An integrative systemic model of resilience and risk, corresponding with Bronfenbrenner's (1986a) systems theory (see Chapter 4), and consistent with the categorisation of protective processes that is presented in Table 5.1, is conceptualised (see Figure 5.1) as being a model that incorporates the principles of systems theory, as well as those associated with the concepts of risk and resilience. It takes into account the dynamic, interactive relationship and multi-directional flow of influence between each of the components. The interactive plasticity acknowledges that it is difficult to decide where to

place specific variables, since factors that boost resilience usually emanate from multiple sources. For example, good intellectual ability is accepted to be primarily genetic in origin, however environmental influences play an important role in how intelligence is developed, displayed and how actively one uses it as a means of successfully adapting to one's environment.

Table 5.1: The most frequently reported protective processes:

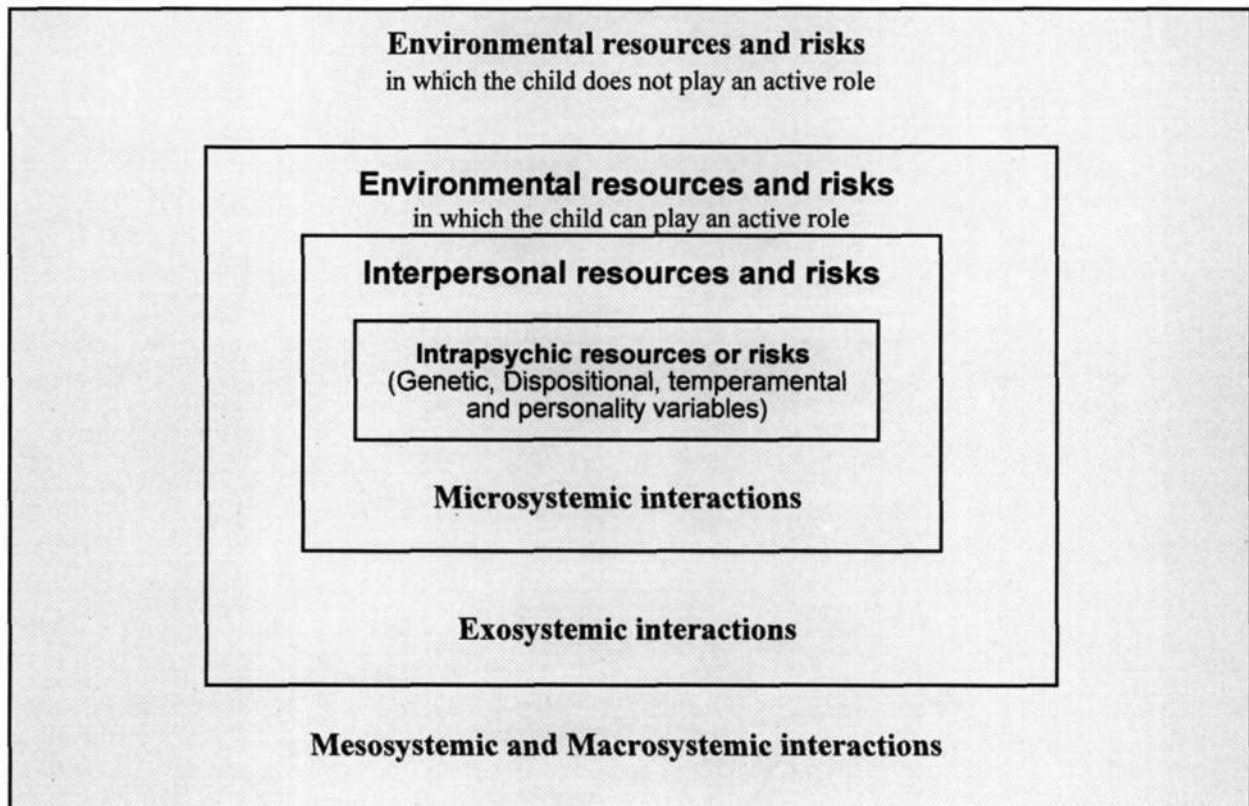
Intrapsychic strengths	Interpersonal skills	Environmental or External supports
<ul style="list-style-type: none"> * Good intellectual skills * Sense of being lovable * Self efficacy and self esteem * Autonomy and sense of control over one's own life * Achievement oriented * Appealing or easy temperament * Talents valued by self and society * A sense of meaning in life * An ability to experience and express a wide range of emotions * Faith and religious affiliations 	<ul style="list-style-type: none"> * Trusting relationships * Secure attachments * Sense of humour * Problem-solving skills * Creative, innovative, resourceful * Social competence * Self regulation * Ability to focus and maintain attention * Empathy and altruism * Recognition of achievement 	<ul style="list-style-type: none"> * Caring supportive parents * Connections to caring and competent adults * Parental encouragement, praise & active involvement * Positive role models * Emotional support outside of the family * Socio-economic advantages * Stable school * Community resources * Access to health facilities * Routine and rituals

This model of resilience incorporates the different kinds of processes (resilience is not a discreet quality) that have been internationally recognised as integral to understanding and utilising the concept of resilience. The child is at the centre of this model, and each of the layers of influence stem from, and between, the child who is an active participant in their own growth and adaptation:

- Certain children have *intrapsychic resources* either because they were born with them, or because they have developed through the interaction of genetic and environmental factors. The genetic, dispositional, temperamental and personality variables function as internal personal strengths or qualities that provide an advantage in terms of boosting the ability to cope and overcome difficulties. These resources function before, during and after the adversity.
- *Interpersonal resources* enhance the quality of microsystemic interactions, make interpersonal transactions satisfying and create opportunities for positively reinforcing social learning that facilitates interdependence (as opposed to either dependance or independence) (Covey, 1994). There are two important components of this category: (i) the ability to access social support; and (ii) action-oriented coping skills to enhance adaptive coping.

- The *environment or context* in which children may be exposed to facilitative (associated with resilience) or destructive (leading to increased vulnerability) experiences, in terms of the provision or lack of supports, resources and structure at the micro-, exo-, and macrosystemic levels (Bronfenbrenner, 1986a).

Figure 5.1: An integrative systemic model of resilience and risk:



5.3. Descriptions of the protective processes

Whichever model of resilience that one may advocate, many of the resilience-enhancing processes are fundamental to both understanding and using the concept of resilience to guide intervention. Therefore, they will be operationally defined and discussed in the following sections. Many of these variables were explicitly incorporated into the intervention programmes that are being evaluated in this study. Both the Sensitisation Programme (SP) and the Structured Group Therapy Programme (SGTP) systematically targeted many of the risk and resilience processes as a means of strengthening individuals (both adults and children), and the communities (Killian et al., 2002, Killian, 2002; Mäddörin, 2000).

5.3.1. Intrapsychic strengths:

It would appear that certain children have intrapsychic or personal characteristics that make them relatively robust. For ease of discussion this are rather simplistically categorised into those that

could have a genetic or physiological aetiology and those internal strength and assets that seem to stem from the child's interaction with others, primarily in terms of the microsystemic interactions. The categorisation is based on the nature/nurture debate and it is acknowledged to be incomplete.

5.3.1.1. Genetic and temperamental internal strengths:

It seems that some children begin life with certain advantages that facilitate and enhance interpersonal interactions and enable better coping in times of difficulty. Some children are born with an *easy or appealing temperament* that facilitates the development of secure attachments with their primary caregivers (Ainsworth, 1972; Bowlby, 1988; Richter et al., 1994). These children tend to be more sociable and outgoing. Enjoying interpersonal appeal and attractiveness, they are more likely to seek and to receive the help and support that they need (Luthar & Zigler, 1991; Masten, 1986; Rutter, 1990; Werner, 1995). Children with easy temperaments begin their pattern of face-to-face, proximal processes (Bronfenbrenner, 1997) with successful adaptations and therefore tend to have less difficulty coping than those children who are born with difficult temperaments (Thomas & Chess, 1984; Trad & Greenblatt, 1990; Werner, 1993;). These children also tend to enjoy a good sense of humour - a feature associated with resilience (Olson & DeFrain, 2000; Mallman, 2002; Masten, 1986).

Children with *good intellectual skills* are more observant, better problem solvers, and have a belief in their own efficacy through repeated success experiences (Kandel, Sarnoff, Mednick, Kirkegaard-Sorenson, Hutchings, Knop, Rosenberg & Schiulsinger, 1988; Luthar & Zigler, 1992; Rutter, 1985). Intelligent children are more likely to be able to understand and attribute a deeper meaning to an adverse event. They are more likely to have an accurate autobiographical memory, which in combination with an easy temperament, enables a child to be more optimistic in outlook, recall positive memories, moments of kindness, to access good role models and to recall their personal achievements (Grotberg, 1995; Mallman, 2002). There may, however, be a window of intellectual ability that is associated with greater resilience - children with above average intelligence do better than those who are below average or who are intellectually gifted.

Some children are more *creative, innovative and naturally curious*. At times, but not invariably, this is linked to intelligence. Creative, curious children exhibit greater resourcefulness (Smith & Carlson, 1997). Parenting and schooling systems that encourage questions, and do not uphold obedience and respect as the ultimate qualities of a well-brought child, augment resilience.

Within first world countries, boys report less stress, and exhibit more distress, until adolescence when this pattern is reversed (Compas et al., 1988; Rutter, 1985). Therefore, gender is considered to be a moderator of risk, in that girls are at decreased risk of developing childhood problems (Rutter, 1987). However, in many developing countries, the excessively high rate of child sexual abuse and gender-based discrimination and violence places girls at greater risk. Furthermore in these contexts, girls are more likely to have to sacrifice their education, take on excessive household responsibilities and chores, and be accorded lower status than boys (UNICEF, 1999). Therefore, girls are probably less resilient than boys in developing countries.

5.3.1.2. Intrapsychic strengths and assets:

There are various environmentally-developed variables that function as internal resources to afford a child intrapsychic strength or advantage in the face of difficulty (Gore & Eckenrode, 1994; Howard & Dryden, 1999; Mallman, 2002; Masten et al., 1990; Rutter, 1984, 1985; Werner & Smith, 1982). These intrapsychic resources are based on contextual relativity. They are not discreet entities but socially constructed, inter-related mechanisms, with much overlap in their occurrence. However, identifying the discreet elements of these strengths enables them to be used in programmes to enhance resilience and increase adaptive coping.

Social competence is the ability to adaptively co-ordinate one's feelings, thoughts and actions (Howard & Dryden, 1999; Masten & Coatsworth, 1998). It comprises elements of both adaptability and social problem solving, involving a set of core skills, attitudes, abilities and feelings that are given functional meaning by the contexts of situation, culture and community (Consortium of School-based Promotion of Social Competence, 1994, p. 275, cited in Howard & Dryden, 1999). The skills needed to be socially competent include (i) an understanding of social norms and customs; (ii) the ability to encode and accurately interpret relevant social cues such as facial expressions, gestures, emotions and interpersonal communications; (iii) perspective taking, empathy and discernment of intentions; (iv) effective social behaviour, appropriate tone of voice and use of proper verbal and non-verbal communication styles; (v) adequate enculturation in terms of respectful and appropriate responsiveness in a wide variety of social situations (Masten et al., 1990). In this regard, the Eurocentric literature places special emphasis on eye contact as playing a facilitatory role in human communication (Doherty-Sneddon, 2004). However, eye contact is perceived as indicating a lack of respect in most African cultures (Meintjes, 2004). While social competence is an aspect of functioning that is difficult to directly measure, it is certainly open to instruction, guidance and reinforcement within the context of child-rearing and intervention

programmes. For example, social skills programmes can effectively enhance social competence in unpopular children (Asher, Parker & Walker, 1996; Erwin, 1993; Mize & Ladd, 1990; Shaffer, 2002). They aim to teach, train and help children to habitually apply social skill processes to improve their peer group acceptance and functioning. The success of these programmes is increased when they also include significant others in the child's life (Asher et al., 1996).

Resilient children have *positive self esteem* and a sense of their own efficacy and competence (Grotberg, 1995). They tend to treat themselves and others with respect (Brooks, 1998). Since they believe in their own ability to make a positive difference, they confront, rather than retreat from challenges, and thereby have the opportunity to learn from their successes and failures. Children develop self confidence and self esteem when they are given positive feedback and encouragement, are recognised for their efforts and have sufficient opportunities to develop mastery in various spheres of functioning. There is a degree of circularity in terms of the origins of self esteem. Self confident children are more optimistic, and being optimistic, they afford themselves more opportunities to gain positive feedback and affirmation of their self confidence.

Problem solving abilities require realistic awareness and appraisal of difficulties, anticipation of consequences and awareness of potential obstacles (Brooks, 1998; Gore & Eckenrode, 1994; Masten et al., 1990; Werner & Smith, 1982). One must be able to (i) correctly identify and understand the nature of a problem; (ii) creatively consider potential solutions and anticipate the impact of these; (iii) implement a solution; and (iv) evaluate the impact and then (v) re-engage in problem solving if the outcome is less than satisfactory. This is a skill that is open to direct training.

Autonomy and an internal locus of control, obviously at age-appropriate levels, concerns a perception that one can deal with and influence what happens to one (Gore & Eckenrode, 1994; Kirby & Fraser, 1997; Masten et al., 1990; Rutter, 1984). An internal locus of control is defined as a belief that one is in charge of one's own destiny (Kirby & Fraser, 1997). By contrast, an external locus of control - a striking feature found in many problem families and individuals (Werner, 1995) - is a belief that one is at the mercy of fate, of external forces that are frequently perceived to be unfair and depriving (Rutter, 1984, p. 60). Of course, ideally some balance is required between the extremes of internal and external locus of control. Nevertheless, one needs to bear in mind that children tend to be more egocentric in their thinking and thus are more vulnerable to feeling responsible when bad things happen to their loved ones. There are variations in cultural conceptions of autonomy and locus of control. American culture places strong value on an internal locus of

control, whilst Chinese children are raised to be more interdependent (Chia, Lytle, Borshiung & Jeen, 1997).

Children who are able to understand and express a wide range of emotions in a socially appropriate manner are more resilient. Children express their feelings in words, actions, play and/or drawing (Aldwin, 1994; Grotberg, 1995; Kransler, 1990; Schaefer & O'Connor, 1983). They generally have a limited vocabulary with which to describe their feelings and experiences, usually only describing themselves as feeling okay, happy, scared, cross, or sad (Kazdin, 2000; Schaefer & O'Connor, 1983). Being able to talk, or play out, difficult past experiences, whilst not dwelling on painful memories, is a basic principle underlying all psychotherapeutic endeavours (Aldwin, 1994; Grotberg, 1999). By externalising distressing experiences one is able to psychically process distressing events and so gain a sense of mastery and control (Herman, 1992; SANTSEP, 2000). Therefore, a goal of most intervention programmes is to enable one to identify a wider range of emotions and be able to express these emotions in social acceptable ways (Aldwin, 1994; Mallman, 2002). The major objective of many of the cognitive reframing therapeutic techniques is to acquire and maintain a sense of identity while simultaneously challenging negative and overwhelming cognitive constructions (Ungar, 2003).

Faith in a higher power or a religious philosophy of life (Anthony, 1987; Coutu, 2002; Mallman, 2002; Werner & Smith, 1982) has been identified as a personal resource, although there could be some debate as to whether this is an internal or external mechanism. A resilient person, adult or child, is likely to have strong spiritual or ideological beliefs that there is a God, a Higher Being, that transcends life on earth (Coutu, 2002). The form that this belief system takes is not important - a child may believe in one God, in many gods or the power of the ancestors. The belief system is usually instrumental in creating a vision of moral order and a sense of justice, in which there is a clear distinction between right and wrong, and acceptable and unacceptable behaviours (Mallman, 2002). In some situations, meaning in life may be rooted in cultural, ideological or political systems. For example, a generation of political activist children were raised with a strong belief in the "Liberation before Education" ideology that was required to rid South Africa of *apartheid* oppression. Similar ideological drivers have been identified in Palestinian children who may have a strong sense of personal worth, heroism and purpose for the benefit of future generations (Punamäki, 1990). Social activist children often feel integrally aligned with the desired outcome of the struggle, war or political uprising and will frequently report ego-syntonic emotions (as opposed

to distress) as they believe that they are active contributors towards the achievement of a stated ideology (Govender & Killian, 2000).

Resilient children tend to have a *sense of purpose and future orientation* (Masten et al., 1990) combined with a sense of usefulness. Werner (1984) identified 'required helpfulness' as a resilience factor, wherein children have set responsibilities and tasks in the home, community, and/or school, taking care of siblings or relatives, or even being responsible for animals or pets. Boys do better when given tasks and clear routines, whereas girls benefit from being given appropriate responsibilities, especially in caring for others (Masten & Coatsworth, 1998). However, careful consideration of what constitutes appropriate tasks and responsibilities for children is needed, especially within the current context of poverty and high prevalence HIV/AIDS communities. Children still need time to be children: to go to school, play with peers and engage in fun child activities. When their tasks and responsibilities deny them these rights, the burden of responsibilities needs urgent review.

Therefore, it seems that children who have good cognitive skills; self-perceptions of competence, worth, confidence and self-efficacy; a positive outlook on life, hopefulness, faith and believe life has meaning; are socially adept; and have adaptable and sociable personality characteristics are better able to cope with adversity (Masten, 2002).

5.3.2. Interpersonal assets and skills:

The variables that are listed under this category include the critically important aspects of object relating that enable a child to distinguish between self and others (Watts, 2002; Winnicott, 1965), and to develop a sense of security, continuity and predictability, trust, belonging and identity (Elder, 1995; Erikson, 1963). The interface between this category of protective processes and the preceding one is artificial as many of the elements can be considered to be primarily inner strengths and resources, as opposed to interpersonal skills and assets. This criticism, however, endorses the principle of multi-directional zones of influence and the dynamic plasticity between the various spheres.

The most frequently identified interpersonal assets and skills include secure attachments; adequate and consistent role models; structure, rules and discipline; a sense of belonging to the family, community and culture; and perceived social support. Traditionally many of these factors have been regarded as being primarily family-based, although with the rapidly changing nature and structure

of the family, some could be established at other systemic levels (Baylis, 2002; Brooks, 1994; Kirby & Fraser, 1997). The development of a *secure attachment* with at least one consistent primary caregiver, be it the mother or other family member, was the first factor found to be associated with resilience (Bowlby, 1988; Masten et al., 1990; Rutter, 1983; Thompson, 2000; Werner & Smith, 1982). A secure attachment with more than one person is also an important resilience factor (Rutter, 1981). Beyond infancy, security of attachment is demonstrated in the time spent with the child to listen, show an interest and be actively involved in what he or she does, thinks, and feels (Cowen, Wyman, Work & Parker, 1990; Grotberg, 1995; Mallman, 2002). It is shown when one recognises a child's achievements (Cook, 1998). When a parent is terminally ill, it is imperative that the child begins to develop a secure attachment with those who will be responsible for their care once the parent has died (Christ, 2001). Many African families adhere customs in which the care of children is vested in several family and community members (Giese et al., 2003). The presence of multiple caregivers who offer consistency, care and secure attachments augurs well for children's emotional development.

The availability of adequate and competent adults who serve as *consistent role models* is important to mould a positive attitude and adaptive coping (Dutra, Forehand, Armistead, Brody, Morse & Clark, 2000; Masten et al., 1990; Rutter, 1979). "Resilient children seem to be especially adept at actively recruiting surrogate parents" (Werner, 1984, p. 70, cited in Smith & Carlson, 1997). Whilst children need to accept the presence of other adults in their lives, it is also imperative that adults make themselves emotionally and socially available to children. Positive role models are instrumental in helping children develop strong moral values (Coutu, 2002; Thompson, 2000) and principles to guide them through life and provide structure and form to their dreams and aspirations. Realistic goal-setting, combined with the motivation and support to strive towards achievements is associated with resilience. While it is beneficial for HIV+ people to publically reveal their status in terms of de-stigmatising the disease, it is also important for young people to have role models who are HIV negative and speak openly about ensuring one's own safety and protection from HIV infection.

Structure, rules and routines make life predictable for children in terms of what happens when and what is expected of them (McCubbin, Thompson, Pirner & McCubbin, 1988). Family rituals associated with mundane daily events such as mealtimes, as well as celebratory rituals for special occasions, can play an important role in promoting resilience (DeFrain, 1999; Killian et al., 2002; Silberberg, 2001). Adequate supervision and monitoring of children's activities is especially

important in high risk settings (Smith & Carlson, 1997). These provide the consistent expectations, rules and consequences (positive and negative) that give children the security and predictability that they need (Loeber & Stouthammer-Loeber, 1986; Olson & DeFrain, 2000, Silberberg, 2001).

A sense of belonging and feeling an integral part of a family, community and culture is a key feature of resilient children (McCubbin et al., 1988; Silberberg, 2001; Thompson, 2000), especially if this provides access to facilities and customs. Being able to trust one's primary caregivers, gives children the 'groundedness' and security that enables them to venture out, explore and engage with the world (Ainsworth, 1972; Bowlby, 1988; Olson & DeFrain, 2000). Winnicott (1965) suggests that children naturally extend this 'groundedness' and sense of security successively to the 'good-enough mother', to transitional objects, and then to the home, school and community. Bronfenbrenner's theory supports this view and adds consideration of children's connectedness with culture and even a sense of historicity (1986b). Since resilient children feel that they belong within their family, home, school and community, they are more likely to actively participate in decision-making processes - an often neglected clause of the CRC (UNICEF, 1989, 1999). A further consequence of having a sense of belonging is that the network of people from whom social support can be sought is significantly broadened, making it more probable that a child in distress can access support (McCubbin et al., 1988; Walsh, 1998). Feeling part of a community and believing that one belongs generates both security and pride. In turn, this precipitates helpfulness, altruistic and prosocial behaviours (DeFrain, 1999; Luthar & Zigler, 1992).

5.3.2.1. Accessing social support:

Perceived social support (the child's own appraisal of social support is critical) and social embeddedness in the form of informal and multi-generational networks of kin and friends enhances resilience. The number and quality of social relationships helps to buffer against adversity (Fantuzzo, Delguido Wiess, Atkins, Meyers & Noome, 1998; Masten et al., 1999; Rutter, 1987; Werner, 1995; Werner & Smith, 2001). Resilient children seek and find emotional support, confident of their right to such support. They discuss difficulties with people whom they trust and respect (Aldwin, 1994; Luthar & Zigler, 1992; Mallman, 2002; Masten et al., 1990; Saler & Skolnick, 1992; Smith & Carlson, 1997). Furthermore, the ability to find and make use of social support outside of the family, utilising informal sources, improves communication skills and problem solving ability. The ability to access social support is significant in predicting resilience (Schrover, Ranchor & Sander, 2003). For example, children who experience high levels of domestic violence and marital discord, show lower levels of psychopathology if they have the benefit of a close relationship with a sibling, or an

adult outside of the nuclear family, usually a grandparent (Jenkins & Smith, 1990). Interestingly, social support systems are especially protective for children from low socio-economic groups (Cicchetti & Nurcombe, 1997), so long as these connections are to prosocial and law-abiding individuals (Masten, 2002).

The mechanisms through which social support operates to lessen risk in children and adults is not entirely clear, although various theoretical explanations have been proposed (Aldwin, 1994; Jenkins, 1992). It is possible that the opportunity to talk about one's problems within a close and caring relationship enables one to externalise difficulties and develop a metacognitive understanding, which in turn creates different cognitive constructions of adverse events and minimises or controls the distress (Gottman, Fainsilber Katz & Hooven, 1996; Oatley & Jenkins, 1996; Ungar, 2003). This hypothesis is consistent with the basic axiomatic principles underlying all psychotherapeutic interventions.

In addition, accessing social support is one of the most frequently occurring secondary coping strategies used by children (Aldwin, 1994; Mallman, 2002; Masten et al., 1990; Smith & Carlson, 1997). The relationship between coping and social support at the time that one experiences major and traumatic life events has been well documented for adults (Horowitz, 1992; Lazarus, 1991). For instance, it has been shown that the likelihood of experiencing a depressive breakdown is significantly reduced if an individual has someone in whom they can confide (Brown & Harris, 1978; Brown et al., 1986). It is also clear that if children witness the adults in their lives coping, they are likely to follow suit. Children suffer distress when they observe their parents in distress.

Social support may also provide a social role that enables the construction and maintenance of an identity that is connected to others and creates a sense of being an integral part of a community. This predisposes one to engage in cooperative action (Scheff, 1997). For example, Gilligan (1998) showed that the progress and resilience of young people in public care is greatly enhanced if children are encouraged to engage in cultural events, sports and other constructive uses of leisure time. Besides being enjoyable and satisfying, constructive activities lead to the establishment of social networks and establish routine and discipline. When children's environments are negative, feeling part of a community and being engaged in cooperative and meaningful activity, may be more difficult to achieve but may be extremely powerful in altering the developmental trajectory to a more adaptive outcome.

5.3.2.2. Adaptive coping in childhood:

The ability to cope in the presence of acute and/or chronic negative circumstances or stressors is clearly associated with resilience (Howard & Dryden, 1999). Coping is considered to be “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person (Lazarus & Folkman, 1984, p. 141). They also include emotional “acts” that are mobilised in response to the subjective experience of stress. In studying adaptive coping in children, the focus has largely been on investigating coping styles and behaviours that are associated with positive adaptation or poor outcomes.

Coping strategies are learned, deliberate and purposeful emotional, cognitive and behavioural responses that enable one to adapt to the environment or to change it (Ryan, 1988, in Smith & Carlson, 1997). Coping begins when an individual faces a stressful event or set of circumstances. It takes place in four stages: (i) A cognitive appraisal of an event to decide on the meaning and implications for one’s well-being. If an event is judged to be stressful, the individual decides if it is controllable. (ii) The individual then selects a coping strategy, by considering the stock of one’s coping resources, the stressor and an assessment of the likely effectiveness of the strategy. (iii) Implementation of the coping strategy. (iv) This is followed by an evaluation of the effectiveness of the strategy in terms of eliminating or reducing the stressor or managing one’s response to the stressful event (Smith & Carlson, 1997).

The literature abounds with methods of categorising coping strategies: active/passive (Lazarus, 1991); approach/avoidant (Horowitz, 1992); or conscious/automatic (Aldwin, 1994). In terms of their functions, coping strategies may be either (i) passive or emotion-focussed: this form of coping usually occurs when one perceives the required adaptation to be beyond one’s ability and control, and so attempts are made to express, regulate or modify the affective responses that were precipitated by the stressor; or, (ii) active or problem-focussed strategies: these consist of attempts to solve the problem and alter the stressful encounter that is considered to be at least partially controllable (Horowitz, 1992; Lazarus, 1991; Punamäki & Puhakka, 1997; Smith & Carlson, 1997). For example, when a parent becomes bedridden with terminal illness, active or problem-focussed strategies may be deployed to assist with washing, feeding and general care of the parent, chatting with the ill parent, and engaging in various activities that make one feel useful. These activities enable the child to feel more in control of the situation, harness emotional resources and allow active engagement with the stressful event. Upon the death of a parent, children may shift to emotion-focussed coping as they feel overwhelmed and are not given tasks and functions that could facilitate active coping

under such extreme distress. For long term successful resolution of extremely distressing events, it is important that there is space for both of these forms of coping strategies.

To understand coping strategies in children, one must take into account individual and societal variables (Brooks, 1998). There is little agreement on the types of coping strategies that children use, beyond recognising that they use a wide variety of strategies to cope with ordinary and significant life events (Aldwin, 1994; Smith & Carlson, 1997). It seems that as children grow, they develop the social and metacognitive skills that impact on the content and variety of coping, and in addition, the environment plays a critical role in terms of the form and structure of social and metacognitive skills (Punamäki & Puhakka, 1997; Vygotsky, 1986). Nevertheless, some of the action-focussed coping strategies appear to be associated with greater resilience (Grotberg, 1995, Lazarus, 1991; Richter et al., 1994). These are listed in Table 5.2.

Table 5.2: Action-focussed coping strategies that promote resilience:

Domain	Coping strategies identified as promoting resilience
Cognitive skills	<ul style="list-style-type: none"> * Ability to focus attention and maintain concentration * An ability to anticipate and plan for the future * Creative problem solving skills that include information gathering, generating options and being able to generate alternative solutions
Emotional skills	<ul style="list-style-type: none"> * Emotional awareness and expressivity * Adaptive use of fantasy * Optimism combined with a tendency to positively reframe events and experiences
Social skills	<ul style="list-style-type: none"> * Good social skills * Access to social support and good role models
Behavioural skills	<ul style="list-style-type: none"> * High energy levels * Impulse control that includes tolerance for delayed gratification * Hobbies, interests, and adaptive use of leisure time
Spiritual skills	<ul style="list-style-type: none"> * Faith strong enough to promote active praying at times of adversity * Being able to think about the meaning of life, beyond the here and now * Access to support from faith-based organisations

The similarities between the literature discussing coping strategies and protective processes are obvious. Adopting problem-focussed strategies could reflect a sense of self efficacy and self worth, autonomy and internal locus of control, a belief in the meaning of life, coupled with optimism about the outcome. It reflects problem solving skills and a coherent knowledge base. Active coping may also reflect social competence and trust in self, others and the future (Erikson, 1963). Secondary

coping reflects access to social support and perhaps also to economic resources so that entertainment, leisure activities and other distractions become possible (Smith & Carlson, 1997).

There are some difficulties associated with these theories in terms of their relevance to understanding children's coping. Some of the underlying assumptions do not readily apply to children. Firstly, these models of coping usually assume that one has the capacity to appraise an event, and then to select a coping strategy from a range of potential responses. However, children probably have a restricted range of coping strategies since some the cognitive and behavioural strategies only become functional with increased maturity and sophistication. Secondly, coping strategies are regarded as being relatively stable across time, situations and developmental stages, whereas this assumption has not been able to stand empirical scrutiny (Aldwin, 1994; Gilligan, 1998; Howard & Dryden, 1999). Thirdly, there is a lack of clarity about whether the appraisal is made at a conscious, unconscious or even automatic neuronal level (Aldwin, 1994). Children have limited ability to conduct cognitive appraisals, to recognise inherent challenges and to assess their own capacity to adapt. They possibly use different coping strategies to adults. They are less able to control many of their stressors by virtue of their relative dependence and immaturity (Aldwin, 1994; Ryan-Wenger, 1992). Strategies that involve perspective taking or regulating one's emotions are acquired gradually with increasing age and maturity, and would be beyond the cognitive maturity of young children. Moreover, it seems that children emulate their primary caregivers (Rutter, 1994) whose capacity to cope adaptively is a significant predictor of children's coping (Gilligan, 1998; Howard & Dryden, 1999). If children have access to good coping role models, they are more likely to cope, whereas when they witness their primary caregivers being unable to cope adaptively, their own levels of distress are exponentially increased. It is also logical to assume that an infinite range of potential coping strategies are used in a situation-specific manner by the many children who cope in a huge variety of circumstances.

5.3.3. External supports and resources:

External supports and resources operate within the three primary systems of the child's world - at microsystemic, mesosystemic and exosystemic levels (Kirby & Fraser, 1997; Bronfenbrenner, 1986a). It is evident that certain families, schools, communities and cultures have protective processes that promote resilience. The availability of supportive people to assist with secondary coping is clearly a part of this system, but since it is the child's appraisal of the coping resource that is important, it was included in the previous section.

5.3.3.1. Resilient families:

Resilient families who successfully cope despite disadvantaged circumstances and live in poor and disrupted communities, serve as important positive role models for children to emulate (Benard & Marshall, 1997; Birkerts, 2000; Masten et al., 1990; Olson & DeFrain, 2000; Silberberg, 2001). On the basis of many cross-cultural studies of family strengths, a variety of strengths have been identified that contribute to personal worth and sense of satisfaction within family members (Dowdney, 2000; Silberberg, 2001): (i) the family circumplex model considers family functioning across the three dimensions of cohesion, flexibility and communications Olson & DeFrain, 2000); (ii) the family strengths model that maintains that strong families have six qualities that contribute to their resilience: commitment to the family; appreciation and affection for each other; positive communication patterns; enjoyable time together; a sense of spiritual well-being and connection; and the ability to manage stress and crisis (Stinnett & DeFrain, 1985, in Silberberg, 2001); and (iii) the Australian Family Strengths Template that empirically established the presence of eight family qualities that are linked to strengths (Silberberg, 2001). Interestingly the Australian Federal Government has invested \$240 million in this project with the aim of building stronger families and communities (ibid.). Again, whichever model one considers the most useful, the focus is usually placed on identifying and operationally defining specific characteristics that enhance family strength and resilience.

Resilient families tend to have three characteristics in common: (i) family members have strong durable beliefs in their ability to control life - i.e. an internal locus of control; (ii) they establish and maintain a sense of order through the implementation of routines for various activities such as meals, bedtimes, accomplishment of household tasks, and so forth; and (iii) there is a system of celebration and acknowledgment of key events in the life of the family and of the individuals in the family. These characteristics serve stabilising functions in times of crises (Fanos & Weiner, 1994; Henson, 2004; Howard & Dryden, 1999; McCubbin et al., 1988; Olson & DeFrain, 2000; Repetti, Taylor & Seeman, 2002; Silberberg, 2001; Saler & Skolnick, 1992).

In addition, research has shown that resilient families (i) use more active coping strategies in which they extend child-care responsibilities beyond the immediate family network during times of distress, assume more flexible maternal roles, have actively-present fathers, enjoy good family cohesion and little inter-parental conflict (Benard & Marshall, 1997; Smith & Carlson, 1997; DeFrain, 1999; Garbarino et al., 1992; Lachman et al., 2002; Masten et al., 1990; Silberberg, 2001; Werner & Smith, 1982); (ii) have clearly delineated parent-child subsystems with firm boundaries so that the child is not expected to be the parent's friend, confidante or to provide emotional support (Silberberg, 2001);

(iii) have parents who provide firm and consistent guidance without repressive or rejecting attitudes (Masten et al., 1990) - this is consistent with Baumrind's characterisation of an authoritative parenting style (1971, in Shaffer, 2002) that has been found to be associated with higher self esteem and improved scholastic and social functioning; (iv) have parents who provide and display an active interest in school and constructive use of leisure time, supporting the child's achievements; (v) have four or fewer children within the family (Lachman et al., 2002; Werner & Smith, 1988) so that sufficient attention can be given to each child, especially during infancy (Smith & Carlson, 1997); (vi) have a manageable maternal work load in terms of the number of children, as well as daily tasks, including duties within and outside the family (Werner & Smith, 2001); (vii) have harmony between parents thereby limiting exposure to conflict and high expressed emotions (Howard & Dryden, 1999; Rutter, 1984; Werner & Smith, 1988); and (viii) enjoy financial stability so that families are able to get on with the business of living and bringing up children without the constant worry about where the next meal will come from (Garbarino et al., 1992; McCubbin et al., 1988; Walsh, 1998). Closely aligned to this variable is having sufficient food, clothing, shelter and medical services available to meet the basic physical needs of children and families. The problem of food security is a major contributor to the social disarray that exists in many high HIV/AIDS prevalence communities.

The structure and institution of the family is being severely challenged by the deaths of parents. The child's relationship with surviving family members is critical in determining the outcome for the children following the death of one or more family members (Saler & Skolnik, 1992; Stein, 2003). Parental death is associated with depression in adulthood, but this effect can be mediated by the surviving adults being empathic, warm and encouraging autonomy (Saler & Skolnik, 1992; Stein, 2003).

5.3.3.2. Effective Schools:

Resilience promoting schools can ameliorate the impact of discordant and disadvantaged homes (APA, 2003; Rutter, 1983). Children spend at least five hours a day at school during term times. Schools, therefore, have the potential to be a major resource for at-risk children. The characteristics associated with effective schools are almost identical to the qualities of schools that build resilience in their learners (Rutter, 1983, Reynolds, 1992, Shaffer, 2002). Effective schools provide children with positive experiences that are associated with success and pleasure in a variety of arenas - academic, sport, cultural, good peer and educator relationships, and shared responsibilities (Erikson, 1963; Howard & Dryden, 1999). Attentive and caring teachers, who are sensitive, supportive, and kind, promote psychosocial adaptation and scholastic achievement by improving the emotional

climate of their classrooms (Reynolds, 1992). Teachers can serve as important positive role models for personal identification, especially if they show an interest in the whole child (Howard & Dryden, 1999; Werner & Smith, 1982). Effective teachers set and monitor work, provide children with opportunities to behave responsibly, give praise and encouragement, and provide a positive caring and caring atmosphere in the classroom and the school (Mortimore & Stoll, 1988; Rutter, Maughan, Mortimore, Ouston & Smith, 1979). A meaningful and relevant curriculum that is perceived to lead towards future success in life motivates children and their parents, whereas high unemployment rates demotivate learners and educators (Reynolds, 1992; Shaffer, 2002;). Schools that promote social competence, problem solving skills, critical thinking, autonomy and a sense of purpose do much to enhance resilience (Bernard, 1999). These outcomes can be achieved by dedicated educators through thematic, experiential, challenging, comprehensive and inclusive curricula (Reynolds, 1992). Resilience can be fostered by focussing on personal strengths, assets and competencies from a multiple intelligence perspective (Gardner, 1993). Self-reflection, co-operation, shared responsibility and a sense of belonging are developed through the use of group teaching/learning techniques (Bernard, 1999). High risk children whose home environments are characterised by hostility, depression, alcohol abuse, and so forth, can experience school as a peaceful haven in which they can be normal kids. A lack of parental monitoring and supervision is associated with externalising disorders (Patterson, Dishion & Reid, 1993) and low school achievement (Ho Sui-Chu & Willms, 1996). In the absence of parental monitoring and supervision, teachers and the classroom setting can provide a co-operative social environment.

The chaotic situation in many South African schools which were run on a system of *Bantu* education during the apartheid years led to school being places of misery for many children (Lourens, 2003). De-motivated authoritarian teachers, themselves victims of an inferior education system, ruled through the use of corporal punishment, frequently never got to know the children in their class by name, and viewed the curricula as irrelevant but dominant (Kolisang & Lourens, 2002). Failure rates were inordinately high, and many school leavers had no future prospects of employment due to the excessively high unemployment rates. The recent shift towards an outcomes based education system is perhaps a step forward in terms of transforming schools to more learner-sensitive environments. However, many educators are under significant stress, due to the rapid rate of educational transformation. The Schools Act of 1997 takes into account some of the features of effective schools and mandates the nature and functioning of the Schools Governing Bodies so that parents, and therefore the community, become active partners in the education of their children.

The educational literature has identified five major strategies to enhance resilience within schools (APA, 2003; Bernard, 1999; Howard & Dryden, 1999): (i) offer opportunities for learners to develop significant relationships with caring adults; (ii) build on social competencies and academic skills to provide children with experiences of mastery and success; (iii) offer opportunities for learners to be meaningfully involved and have responsible roles; (iv) work to identify, collaborate with and co-ordinate support services for children; (v) strive to 'do no harm' by ensuring that the structures, expectations, policies and procedures do not add to the risks already experienced by children (Howard & Dryden, 1999, p .9). Working within South African schools, Kolisang and Lourens (2002) have developed an effective, but resource intensive programme that applies the seven habits of highly effective people (Covey, 1994) to enhance the sensitivity of educators and to create emotionally safe classrooms.

5.3.3.3. Community and cultural resilience:

The external protective processes at a community level are not well documented, except in terms of the 'opposite of risk model' of resilience. Many of the resilience enhancing processes that pertain to the school environment are applicable to the community context. Ungar (2003) demonstrated the applicability of Bronfenbrenner's systems theory by showing that if individuals perceive themselves to be competent in accessing health services (and other social services), they are more able to maintain resilience (ibid.). Whereas, when communities feel that they are impotent in terms of accessing services, this negatively impacts on their general well-being, their sense of self efficacy and their willingness to participate in community development projects. Given the South African government's recalcitrant attitude to providing treatment for HIV+ individuals, this may have serious ramifications in terms of the resilience of individuals, families and the community as a whole. Ungar's (2003) qualitative study proposed that resilience is the outcome of the negotiation between the individual and their environment, and if these negotiations fail, resilience is severely compromised, and the cognitive constructions of self and community are profoundly eroded.

Cultural resilience is a relatively new term, however the basic underlying concepts are as old as culture itself. Implicit and critically important in many traditional life styles is the belief that "our children are gifts from Our Creator and it is the family, community, school and tribe's responsibility to nurture, protect, and guide them" (HeavyRunner & Morris, 1997, p.1). A culture's world view is grounded in fundamental beliefs that guide and shape daily life experiences. The valid and positive role that culture plays in supporting youth and tapping their resilience has long been recognised by traditional peoples. HeavyRunner and Morris (1997) have identified ten innate and natural aspects

of resilience promoting traditional cultural beliefs: spirituality; child-rearing/extended family; respect for nature; veneration of age/wisdom/tradition; generosity and sharing; cooperation/group harmony; autonomy/respect for others; composure/patience; relativity of time; and non-verbal communication.

Although their work is based on American Indian culture, there are clear similarities between these values, and the *Ubuntu* values held in traditional African communities (de la Harpe et al., 1998; Mkhize, 2004). The concept of *Ubuntu* is an African ethic that has been widely accepted, both at the level of policy-makers and at grass roots. *Ubuntu* is regarded by most community members as an admirable quality to which they aspire (Avilia & Combs, 1985). However, the concept does not have a well articulated theoretical base according to which it can be implemented. As Dhlomo (1991, p. 49) says: "It is true that we all talk about *Ubuntu*, but no-one amongst us has yet grasped the axiom." However, Dhlomo goes on to encourage the development of the theoretical framework that would enable a revitalisation and enhanced awareness of the concept.

Ubuntu is an ethic that informs a way of being, a way of life and a tradition that impacts at both the individual and group levels (Mbigi & Maree, 1995; Mkhize, 2004). One definition of *Ubuntu* stands out in its simplicity as well as its' pervasive implication - Vilakazi defines *Ubuntu* as "humanism ... a belief in and respect for people, with a special focus on the individual's value, dignity, safety, well-being, health, love and potential for development" (1991, p. 6). The various facets of *Ubuntu* include (i) *Solidarity*: The principle of solidarity appears in all definitions of *Ubuntu*: "a man is a man through others"(Mbigi & Maree, 1995, p. 41); "I am because they are; and they are because I am" (Oakly-Smith, 1991, p. 45). (ii) Interpersonal relationships have the right (entitlement) to *unconditional respect, dignity, acceptance and care from others* (Mbigi & Maree, 1995, p. 41). (iii) *Dialogue* between people and groups is essential in that it enables co-operation and participation, making group/team work an essential mechanism for interaction, decision making, etc (Mbiti, 1988; Mittner, 1995). (iv) There are strong expectations from others to *conform with the group's survival requirements*, in return for the security which the group has to offer in terms of collective realisation of goals (Mbigi & Maree, 1995; Mittner, 1995). (v) There is a *balance between material and spiritual realities* (Mbiti, 1988). (vi) It is *group-focussed*, with little concern for individual aspirations and goals, nor with self realisation (Mbigi & Maree, 1995; Mittner, 1995).

Through the application of *Ubuntu*, groups are considered to be able to ensure their own resilience and survival in an organised, protective and dignified manner. In tribal African societies, groups had to organise to survive against oppression, placing high value on solidarity, conformity and caring for

one another (Mbigi and Maree, 1995). Vilakazi (1991) suggests that *Ubuntu* is most applicable in small homogenous communities that are not divided by social class; where leadership adopts participative management styles (as opposed to authoritarian or autocratic styles); where there are opportunities for dialogue while planning collectively and according to fair guidelines in the delegation of tasks and responsibilities; where there can be equitable distribution of profits; where people are willing to share generously in a spirit of hospitality, with empathy and equality being highly valued; and where beliefs, traditions and rituals that maintain the climate and cohesiveness of the community at a high level (p. 9). The concept of *Ubuntu* could therefore be highly relevant for community interventions as it encapsulates the empirical data on which the concept of community resilience is based. Certainly the outcome of an effective community-based intervention would be consistent with the principles of *Ubuntu*. In terms of the AIDS pandemic there is evidence that people at grass roots levels have repeatedly demonstrated their willingness to help and be involved (Phiri et al., 2000).

The consistency between these features and the factors that the western world has identified as promoting resilience is remarkable. The interconnectedness that is embodied in the cultural spirituality is an especially important feature. Many traditional rituals mark the rites of passage (for example, a child's birth and naming, puberty rites, funeral ceremonies, etc.) by explicitly acknowledging that all life is interconnected. Entire villages and tribes may assemble for these ceremonies that begin by calling-in and welcoming the ancestors (HeavyRunner & Morris, 1997).

There are also cultural variations in child-rearing patterns (Super & Harkness, 1994). One culture may praise children for finding their own solution and demonstrating independence, another provides loving support and helps children face adversity (Grotberg, 1999). However, there are also various cultural practices that increase risk: severe punishment; excluding children from various activities in an endeavour to protect them from the harsh realities of life and death; focus on obedience to the exclusion of the development of inner strengths and independence; not discussing sexuality with children; and leaving children to solve their own problems, with no mechanisms through which children can ask for assistance.

Community development work is usually grounded in the principles of empowerment (Gibbs, 1995). Somewhat simplistically, one can think of empowerment as being based on two axiomatic convictions: (i) Given a nurturing environment that taps into universal strengths, all people have an innate capacity for change and transformation (Benard & Marshall, 1997; Grotberg, 1999; Mills,

1995); and (ii) Human potential is always there, waiting to be discovered and invited forth even in situations of dire adversity (Purkey & Stanley, 1995, in Benard & Marshall, 1997). Empowerment is usually achieved through community organisation, democratic decision-making processes, and active participation of community members in a sustained and responsible manner (Gibbs, 1995; Higson-Smith & Killian, 1999).

5.4. Measuring resilience:

The complexities of defining resilience are reflected in the problems of measurement. The usual form of measurement is to check for the presence of various protective processes such as positive self esteem, social skills, parental bonding, etc. (Cluver, 2003; Dube, 2003; Richter et al., 1994; Wild, 2001). Studies of resilience tend to include several measures, each tapping a different aspect of the child's functioning. Alternatively, psychometric tests of childhood psychopathology have been used either to focus on specific forms of childhood pathology such as PTSD, depression, manifest anxiety, etc (Dube, 2003), or to generally screen for a range of childhood pathologies. The use of these tests assume that either the absence of pathology reflects resilience (Rutter, 1987), or when used as part of test-retest experimental designs, the reduction in pathology is considered to reflect increased resilience (Kazdin, 2000).

Acknowledging some of the inherent difficulties of the above-mentioned approaches to measuring resilience, a further genre of tests emerged in which certain test items, usually derived from other standardised tests, are identified as being especially associated with resilience. For example, the Strengths and Difficulties Questionnaires (Goodman, 1997) is an abbreviated form of more comprehensive measures of psychological distress (such as the Child Behaviour Checklist) that takes only ten minutes to administer (Cluver, 2003). The brevity of this questionnaire has decided appeal, but it is usually used in combination with other measures (*ibid.*). The International Resilience Project (Richter et al., 1994) constructed a set of 15 situations of adversity that were read to children and parents who were then asked to respond to a set of open-ended questions pertaining to the situations. The responses were then judged to reflect resilience promoting, mixed or non-resilience enhancing behaviours. Lazarus (1991) supported this method of measuring resilience maintaining that situation specific measures would provide the richest portrait of coping strategies. However, despite their theoretical appeal, these models of measuring resilience still do not enjoy adequate levels of reliability or validity.

There are at least major research projects currently in process that are attempting to identify ways to measure the impact of PSS, and indirectly to measure resilience (Dube, 2003, Snider, 2004; Williamson, 2003). At this stage, measuring resilience is a difficult endeavour.

5.5. Mechanisms through which resilience can be developed

There is little doubt that the empirical and theoretical exploration of resilience has been a major contribution to understanding child development. However, despite having a large literature that explores the concept, there is still no consistent vocabulary, conceptual framework or methodological approach (Coutu, 2002; Zimmerman & Arunkumar, 1994). Just as the term stress lost its scientific meaning (Rutter, 1983), the concept of resilience runs the risk of becoming an unverified popularised notion (Cicchetti & Garmezy, 1993; Coutu, 2002). There is still much confusion about what constitutes resilience.

Many of the identified protective processes are inflected with normative, middle-class values (Howard & Dryden, 1999). Rutter (1990, 1999) proposes that the empirical studies are useful in identifying the general processes through which children develop resilience, but that the precise nature of these will vary across contexts. For example, family support and care is regarded as a strong predictor of resilience, but the exact manner in which family care and support is interpreted and enacted varies in different historical, social and cultural contexts (Super & Harkness, 1994). Participatory action research affords one the opportunity to explore with community members the contextually and culturally specific ways in which, for example, family care and support could be achieved.

Resilience is a dynamic and unfolding process in which individuals and their environment interact to produce beneficial outcomes. Resilience is "not something some children simply have a lot of" (Sroufe, 1997, p. 256), rather it seems to be a capacity to cope and bounce back after periods of difficulty and it draws on the total context of internal and environmental influences. The person evolves the capacity to stay organised, to actively cope, and to maintain positive expectations in the face of challenges and across successive periods of adaptation. It is an acquired capacity influenced by on-going changes in context (Sroufe, 1997, p. 256). Adopting the position that it is a learned phenomenon enables the development of intervention programmes that have clear aims and objectives. One can explicitly focus on building capacity and enhancing individual, family and community abilities to face adversity and to foster inner strengths (Benard & Marshall, 1997; Garmezy et al., 1984; Grotberg, 1999, 1995; Werner & Smith, 2001). The empirical work in this field

has helped to identify internal and external mechanisms that appear to enable children to deal better with their difficulties. For example, a simple, but effective, resilience enhancing technique requires children, and adults, to build resilience and develop self esteem by generating a set of self-descriptive statement: “I am...”; “I can...” ; and “I have ...” (Grotberg, 1995; Killian et al., 2002;). Grotberg (1999, 1995) advocated this method of translating theory into practice and developing resilience in individual children, families and communities. A child can be encouraged to develop resilience by being trained to acknowledge personal strengths and assets by cognitively reframing their life experiences into strengths-based formulations. The International Resilience Project has endorsed this simple yet effective technique as a method of promoting resilience (Grotberg, 1999).

From a broader perspective, there are four pathways through which resilience and protective processes can exert an influence, each of which may operate at an internal and/or external level (Masten, 2002; Rutter, 1987, 1990):

- **Reduction of exposure to risk:** Protection is afforded to some children simply by reducing their exposure to risk. Family and community variables are significant in terms of this form of resilience. For example, some children experience minimal exposure to risk by virtue of their family or community circumstances. They live in close secure families, in which hostility is handled adaptively and their basic physical, emotional and social needs are met. This pathway to resilience enhancement is especially important at exo-, and macrosystemic levels. If a nation truly embraces the principles of the CRC, children are protected from many risks. Strong advocacy towards reduction of children’s exposure to risk is needed and will always form an integral aspect of an effective intervention. Examples of risk-focused strategies of intervention include the provision of adequate antenatal, health and social care, prevention of child abuse and neglect, and programmes that reduce bullying, crime and violence, and so forth (Masten 2002).
- **Minimising negative chain reactions:** A stressful event or experience often sets in motion a sequence of negative chain reactions, resulting in the cumulation of risks from both external and internal sources. An example of this form of resilience boosting is offering psychosocial support to children who have recently, or soon will suffer, the death of their primary caregiver (Germann & Mäddörin, 2002). Poverty alleviation programmes aim to reduce negative chain reactions associated with poverty (Toomey & Chrisite, 1990) by providing food security, adequate sanitation, health resources and mental stimulation to communities who are considered to be at high risk.

- **Promotion of self esteem and self efficacy:** Positive self esteem is recognised as being critically important to boost resilience. One method of promoting self esteem is through enhancing opportunities for accomplishment and a sense of achievement, by developing competency and success in various spheres of one's life (Brooks, 1998; Erikson, 1963). Experiential programmes offer opportunities to create cognitive and emotional shifts in the self concept and enhance self esteem through the provision of challenges within a supportive and facilitative environment. The Masiye Camp Model is a clear example of this form of intervention programme (PACT, 2002; Think Tank, 2000). These often take the form of asset-based strategies that increase access to resources such as schools, libraries and recreation centres (Masten, 2002)
- **Provision of opportunities for positive relationships and experiences** offer children access to needed resources and new directions in life. The goals of most community development programmes are consistent with this form of resilience building. Their major goal is empowerment through participation in programmes that enable supportive, caring and focused interpersonal interactions and the opportunity to experience new ways of being. When people develop their social networks through participation in positive and supportive processes, they develop greater resilience (Catholic AIDS Action, 2003). Masten (2002, p. 13) describes these strategies as the "big guns" for change as they adopt a more holistic perspective that attempts to restore, engage or mobilise the power of human adaptational systems for children. The examples given by Masten (2002) include programmes that improve the bonds with competent and caring adults and programmes that build self-efficacy through experiences of success and the development of talents and competence.

All of these pathways to building resilience are relevant to the current research programme. The children and communities in this research are immersed in hardship. Just as Straker, Moosa, Becker and Nkwale (1992) challenged the relevance of the concept of post traumatic stress disorder for South African populations who lived in circumstances of continuous traumatic stress, researchers and community workers need to acknowledge the co-occurrence of numerous profound risks and hardships for children living in high prevalence HIV/AIDS communities. The real-life context is that individuals, families and communities pass in and out of difficult and challenging circumstances on a more or less continuous basis with little respite (Richter et al., 1994). Little is actually known about either resilience or coping in such dire circumstances (Foster & Williamson, 2000; Stein, 2003; Wild, 2001). Therefore, in developing an intervention programme it was necessary to include as many of the mechanisms to reduce risk and build resilience as possible. The pioneering work of Mădörin

(2000) was considered to be especially useful in this regard. Working with AIDS orphans in Tanzania, Mäddörin developed a structured group therapy programme that systematically enabled children to deal with their experiences of risk and to enhancing the development of resilience (ibid.). Mäddörin's programme was adapted for the South African context, with the aim of further developing the resilience enhancing variables and including a greater focus on cultural rootedness (Killian, 2002). The resilience promoting strategies that are incorporated in this community based intervention programme are listed Table 5.3, where the reader will note the marked similarity with the protective processes that tabulated in Table 5.1.

5.6. Translating theory into practice:

This dissertation is an evaluation of an intervention that aims to apply the concepts of resilience from the perspectives of the strengths-based and protective processes models so that practical tools can be incorporated into the everyday work of development projects (Grotberg, 1995). A firm belief in the basic principles of empowerment (Benard & Marshall, 1997) aimed to value respect, participation and care as critical aspects of all interactions with community members, be they children or adults. These values were regarded as the important mechanisms through which change, development and transformation could be possible: (i) caring relationships provide love, consistent support, compassion, and trust; (ii) high expectations convey respect, provide guidance and build on the strengths of each person, family and community; (iii) opportunities for participation and contribution provide meaningful responsibilities, real decision-making power, a sense of ownership and belonging, and ultimately, a sense of spiritual connectedness and meaning (Benard, 1996; Benard & Marshall, 1997).

Table 5.3: Resilience promoting processes integrated into the current community based intervention programme:

Inner personal strengths	Social interpersonal skills	Facilitative environment
<ul style="list-style-type: none"> * Self esteem * Problem solving skills * Emotional expressivity * Sense of purpose and future orientation * Faith in a higher power * Curiosity and creativity * Opportunities to express grief and other emotions associated with distress. * Problem-solving skills 	<ul style="list-style-type: none"> * Social competence * Opportunities to form friendships and break alienation * Structure, rules and routines * Sense of belonging, breaking down alienation * Perceived social support * Time to celebrate 	<ul style="list-style-type: none"> * Develop attachments to members of the community * Availability of competent, sensitive adults as good role models * Empowerment * Participation and joint decision making * Increased sensitivity to the psychosocial needs of children * Provision of recreational activities

A significant conclusion from the International Resilience Research Project was that resilient individuals are helped to become resilient. Although, Grotberg (1995) defined resilience as the universal capacity that allows a person, group, or community to prevent, minimize or overcome the damaging effects of adversity, it is important that partnerships be formed to facilitate this process. People can be helped to draw on their inner resources and strengths within a structure of guidance, direction and support (Grotberg, 1999; Masten, 2002).

The concept of psychosocial support (PSS) became the central mechanism through which the impact of community-based initiatives could usefully translate the theoretical literature on resilience with grass-root practice. While children's educational and physical needs are more obvious, there has been a tendency to neglect their psychological, social, and spiritual needs. The study of risk and resilience has thrown into sharp focus the need to address these psychosocial needs. The theoretical literature enables systematic building of resilience in children and communities. The dire predictions associated with the risk literature indicate that there will be several generations of children who will loose out on the basic socialisation processes that are integral to the functioning of a civil society. On the other hand, the resilience literature offers several meaningful ways in which effective interventions can meet the needs of children, families and communities rendered vulnerable through the HIV/AIDS pandemic. This intervention programme aimed to target several aspects of microsystemic interactions in order to build and enhance resilience and minimise the impact of the risks to which children were being exposed. Having developed the programme, it was important to shift the focus away from adversity, illness (HIV/AIDS) and risk to resilience and coping, and to look at what works and what does not work (Ungar, 2003).

SECTION III

The intervention programme and context of evaluation

In this section of the dissertation, the programme development is described, and the two programmes that were the specific focus of this research are outlined (with a more detailed overview in Appendices D and E). The reader will note that in accordance with contextually based theories of child development, it was essential to integrate microsystemic and macrosystemic strategies into this holistic intervention programme (Chapter 6). This however makes the reporting of the procedure complex, and so the chapter on programme development is followed by an outline of the overall intervention/research programme (Chapter 7).

By beginning with a presentation of the broader research methodology, it is hoped that the reader will be able to track the process of grounding the research within the partnering communities. The basic research ethic was one of participatory action research, as this was considered to be the optimal method through which communities could be strengthened to offer psychosocial support to their vulnerable children. It was thus imperative that community members viewed themselves as co-participants and co-researchers in the process. They were regularly consulted and gave advice. Their information was valued as being contextually rich and relevant in terms of offering support to their vulnerable children. The reader will see that the process, described in Chapter 7, continually wrestled with the tensions created in real world research contexts, in which the rigours of research could not be compromised by the need to empower and enrich the participants in the research. This was difficult and time-consuming, but ultimately increased the effectiveness of the two programmes - the Sensitisation Programme (SP) and the Structured Group Therapy Programme (SGTP) - that are essentially the focus of this research. The evaluations of these two programmes are described in Sections 4 and 5 respectively of this dissertation.

Chapter 6

Programme Development

"It is impossible to overemphasize or exaggerate the scope and complexity of challenges faced by children affected by HIV/AIDS and by the families, communities and governments responsible for them" (Atwood, 1997, p.1)

Over the last few years many programmes have developed in response to the dire needs of children who have frequently been perceived to be the helpless victims of the HIV/AIDS pandemic (Germann, 2002). Care and support in crisis situations usually begins by trying to meet basic physical needs, in much the same manner as the Red Cross has assisted in disaster areas for many decades. War nurseries, refugee camps, and children's homes are also reflective of this form of intervention. In many of these circumstances, children's psychosocial needs have been neglected (Burr & Montgomery, 2003). For example, in many parts of the world institutional care has repeatedly been shown to be less than satisfactory due to its disregard of children's psychosocial needs (Burr & Montgomery, 2003; Dunn et al., 2003). Institutional care has the added disadvantage of not being economically viable (UNICEF, 1999). While crisis and reactive programming usually addresses children's basic physical and educational needs, there is little focus on their emotional, social and spiritual needs. Meeting children's physical and educational needs is a resource-intensive activity, that is usually accompanied by the assumption that their psychosocial needs are automatically met through the compassionate care of those who are in daily contact with the children. This assumption is seldom valid.

Recognising the need to promote effective interventions with children affected by HIV/AIDS, various international aid organisations developed a strategic framework to guide appropriate programming (Hunter & Williamson, 2002). This strategic framework is the co-ordinated plan offered by the major international stakeholders (including UNAIDS, UNICEF and USAID) and is consistent with other intervention objectives that have been suggested (Family Health International, 2001). It also complements the United Nations General Assembly Declaration of Commitment (UNGASS, 2001) in which policy developers from the United Nations, governments and NGO's undertook to develop national policies and strategies that build the ability of all key-stakeholders to support children infected with and affected by HIV/AIDS. Implementation by 2005 was agreed upon. Some African countries are making progress towards the achievement of these goals (Germann & Stally, 2003).

The challenges posed by the enormity of the HIV/AIDS pandemic dictate that comprehensive, cost-effective approaches based on coordinated partnerships in which community mobilisation occurs (Family Health International, 2001). To this end, the purpose of both the strategic framework and the UNGASS declaration is to enhance the global, national and local responses by providing guidance and a common point of reference for those working with vulnerable children, families and communities affected by HIV/AIDS (Hunter & Williamson, 2002; UNICEF, 1999; USAID & the Synergy Project of TVT Associates, 2001). The five strategies, contained in the strategic framework, reflect the evolving and dynamic principles that should guide effective intervention strategies for children¹² (Hunter & Williamson, 2002; USAID, 2004):

Strategy 1: Strengthen and support the capacity of families to protect and care for their children.

This strategy acknowledges the critical role of the family. The objective is to empower families to provide care, support and protection to vulnerable children through economic strengthening and psychosocial support.

Strategy 2: Mobilise and strengthen community-based responses by enabling communities to organise themselves to identify the most vulnerable children and to channel local and external resources to the most needy. Community mobilisation has become a key activity in many effective intervention programmes (Aggleton & Warwick, 2003; Hunter & Williamson, 2002; Levine & Foster, 1998; Mann, 2002).

Strategy 3: Strengthen the capacity of children and young people to meet their own needs, to fulfill their right to participation, to integrally involve them in the solution, and to ensure that they remain in education for as long as possible. This strategy is in line with the CRC (UNICEF, 1989) and sees children as part of the solution.

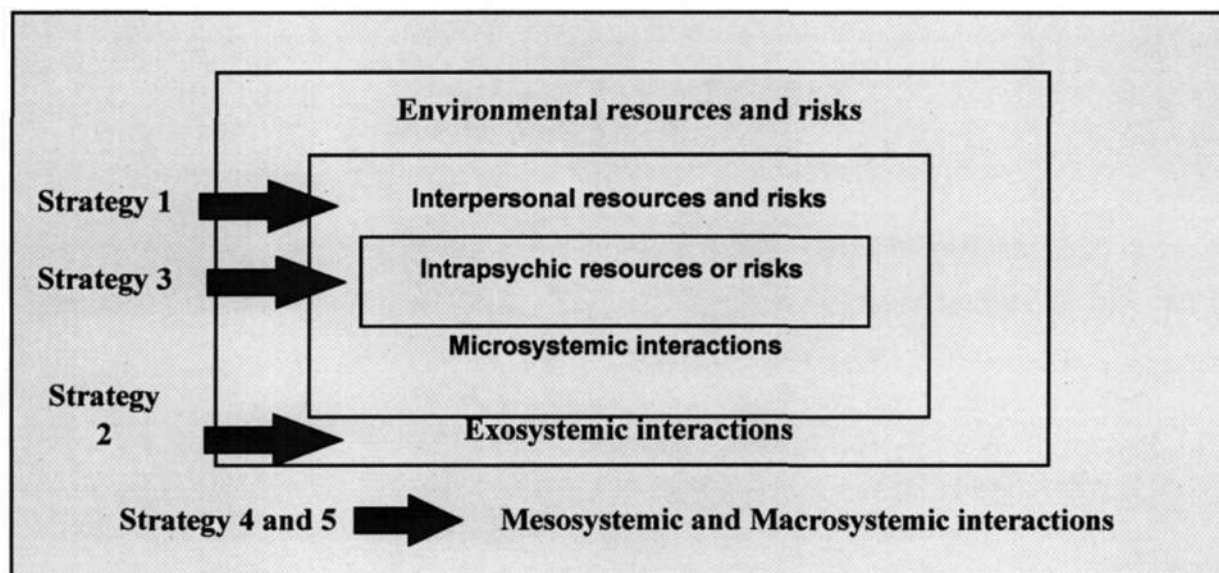
Strategy 4: Ensure that governments develop appropriate policies to include programmatic frameworks and essential services for the most vulnerable children. The UNGASS Declaration of Commitment (2001) services this strategic initiative.

Strategy 5: Raise awareness within societies to create facilitative and compassionate environments that generate shared responsibility and decrease stigma and discrimination. This overarching aim is consistent with the other five strategies and would usually be implemented through social and health service provision, community mobilisation, media programmes and microsystemic interactions.

¹²The underlining principles that inform these strategies are presented in Appendix A.

Using Bronfenbrenner's (1986b) theory of the social ecology of child development, the inter-relationship between the five basic strategies can be diagrammatically (see Figure 6.1). The axiomatic principles underlying systemic theories¹³ explain the dynamic, inter-active and multi-directional zones of influence between these strategies/systems. Strategy 4 can be conceptualised as being focussed primarily at the macro/exosystemic levels, whilst strategies 1, 2, and 3 operate principally within microsystems. Strategy 5 needs synergistic programming across all of the systemic levels. Child-sensitive policies and essential services at global, national and local level, together with increased awareness, compassion, understanding and commitment at all systemic levels, would meaningfully reduce the adversities and risks experienced by vulnerable children. This would mediate risk variables and build individual and group resilience.

Figure 6.1: Conceptualising the strategic framework within a systemic perspective



Operationalising the strategies requires the mobilising and strengthening of local initiatives (Hunter & Williamson, 2002). There is a need to design culturally and epidemiologically specific responses by adapting interventions for local conditions at both national and community levels (UNAIDS Best Practice Collection, 1997). While some programmes have been identified as “best practice models”

¹³ The systems approach is based on the premises that (i) development is based on a complex network of multidirectional interactions between all systems in a society, (ii) individuals are active participants in their own socialisation; and (iii) all systems are dynamic adaptive structures that simultaneously influence each other in a circular and reciprocal fashion in an endeavour to find equilibrium.

(USAID, 2001), the grassroots circumstances are complex and cut across all levels of community functioning. Imported models are only likely to be effective if they include local stakeholders who endorse and support the intervention (Duffy & Wong, 2000). Interventions that draw on and incorporate local wisdom and experience have the greatest probability of being both effective and sustainable (Cook, 1998). There needs to be a sense of ownership among the stakeholders who live and work within the affected communities (Duffy & Wong, 2000; Meintjes, 2003).

Of course, there is no need to reinvent the wheel each time an intervention is planned. Valuable lessons have been learnt from earlier responses that attempted to limit the destructive impact of HIV/AIDS since the beginning of pandemic in the mid 1980's (Family Health International, 2001). One such lesson is that synergistic programming is a means through which various policies and intervention programmes can work together harmoniously in a co-ordinated and collaborative manner to meet the needs of the whole child across all systemic levels. Synergistic programming aims to create a facilitative environment in a mutually reinforcing manner so that comprehensive integrated care is offered to vulnerable children, their families and communities. In applying the strategic initiatives identified by the international consortium (Hunter & Williamson, 2002), one can discern various operating principles (see Appendix A) that inform effective interventions. These principles encourage synergistic programming by specifying that the various components of integrated intervention strategies need to be co-ordinated and collaborative (UNICEF, 2001). Increased participation, transparency and accountability at all levels is necessary to integrate these principles into programmatic interventions (USAID Office of Sustainable Development, 2002). There is no doubt that the strengthening of cross-sectoral linkages increases the impact of intervention programmes and generates greater sustainability.

In terms of the strategic framework, there are two strata of ecological concern: (i) macro/exosystemic commitment that generates and implements policies to enhance general well-being; and (ii) microsystemic participation and assistance to mobilise and strengthen supportive interactions between children, families, communities and service providers.

6.1. Macro/exosystemic components of intervention:

At the macrosystemic level, the international, national and local governments can significantly contribute to the well-being of vulnerable children and their families. Bronfenbrenner (1986)

advocated the need for macrosystemic intervention to meaningfully alter the social ecology of an individual child. Many regard the implementation of national policies and services as pre-requisites for creating facilitative environments for children can grow to their potential. Synergistic programming is made possible in various ways (Family Health International, 2001; Hunter & Williamson, 2002; UNICEF, 2001). For example, the CINDI Network in Pietermaritzburg has over 80 partners from government, local government, NGO and CBO organisations who collaborate, share skills, offer support to each other and the service recipients so that collectively members meet the needs of vulnerable children in this city. This network serves as a 'good practice' example for synergistic programming in a non-competitive and focussed manner.

The *human and children's rights perspectives* are recognised as essential to the success of programmes for vulnerable children (Family Health International, 2001). Most governments are signatories to human and children's rights legislation and have international obligations to create environments to protect, respect and uphold children's rights. Explicit in all human rights documents, and in the South African Constitution, is the prevention of all forms of systemic or infrastructural discrimination. Theoretically, this protects vulnerable children from stigmatisation due to their socio-economic or health status. Signatory governments are obliged to provide multi-sectoral and integrated health, education, agriculture, development and social services in non-discriminatory and non-exploitative ways.

There is little doubt that the single most significant difference that could be made to the lives of vulnerable children would be to offer *socio-economic support*. HIV/AIDS is a poverty-related illness that creates a rapid decline in living conditions (Guthrie, 2003). When children and families are forced to focus on the day-to-day struggle to meet their most basic needs, where there is no food security, their attention cannot be stretched beyond immediate survival (Giese et al., 2003; Guthrie, 2003). Poverty greatly exacerbates the cumulative impact of the risk variables on children and communities. HIV/AIDS affected children consistently report that their greatest needs are related directly or indirectly to socio-economic factors (Clacherty & Associates, 2001; Giese et al., 2003). It is the loss of income, shelter, educational access, social alienation and exclusion, and other forms of deprivation that leads to immense suffering and hardship for children.

Social grants are essential components of meaningful intervention (Giese & Meintjes, 2003;

Proudlock & Rosa, 2003). However, they are insufficient and disempowering when they are not combined with the means through which long-term self-sufficiency and dignity can be achieved. There is a need for urgent review of the eligibility criteria for social grants, with methods of fast-tracking applications for the most needy children and their families (Giese & Meintjes, 2003). In addition, this should be combined with programmes to establish small, medium and micro agricultural and income generating projects that serve to improve economic and nutritional status.

Access to quality education is critically important as this is the vehicle through which children can be socially integrated, provide mental and physical stimulation, and significantly enhance children's overall competence. Universal access to education could be strongly supported by offering incentives to schools that offer quality education to children living in poverty (UNICEF, 2001) would enhance current and future stability. Strategies are needed to prevent school drop-out, provide care for sick relatives while children are at school, and eradicate educationally-based discrimination through the abolition of school fees. Families require greater awareness of the need for education and the consistent routine offered by familiar schools, as a means of enhancing resilience and sustaining morale through difficult periods of transition and change (Gilborn & Nyonyintomo, 2000).

The primary objective in terms of health care is extending the *quality and duration of life for parents and guardians*, as this would postpone orphanhood. Children cope better when they have loving and consistent parenting in the first three to five years of their lives (Rutter, 1983). With improved quality of life, HIV+ people have a better chance of warding off the socioeconomic and emotional impact of AIDS-related illness and death (Atwood, 2001; Giese et al., 2003). Resilience is increased when children are prepared for the death of loved ones and informed about care provisions made for them (Foster & Williamson, 2000; Hunter & Williamson, 2002). Parents must be encouraged to make provision for the future care of their children and consider the long-term costs of elaborate funeral rites.

Clinical and preventive health care services must include nutritional support, VCT, palliative care, home-based care, immunisation programmes and other health outreach interventions (Atwood, 2003; Giese & Meintjes, 2003). Babies born to HIV+ mothers need extra nutritional support. All children require immunisations. The World Health Organisation's recent focus on integrated management of childhood illness (IMCI) is a step towards synergistic programming (WHO, 2003).

Information dissemination programmes equip people to make informed decisions about their health..

Internationally endorsed strategic frameworks prioritise strengthening extended families and communities rather than resorting to inappropriate institutionalisation (Dunn et al., 2003). Grandparents, widows and children, frequently the primary caregivers, are especially vulnerable, socially-excluded subgroups who need policies that fast stream their access to resources and support (Levine & Foster, 1998; Proudlock & Rosa, 2003). In fact, many households are run as *de facto* child-headed households, as the adults are too old or infirm to shoulder the responsibilities of child care (Desmond et al., 2003). There needs to be greater awareness of inheritance and property rights (Foster & Williamson, 2000). Social services need to gear their service delivery for people who survive on meagre pensions and social grants and so do not have the money to get into towns to register births and deaths to apply for grants (Guthrie, 2003). These population subgroups have different health care needs (Ewing, 2003), which should inform service delivery policies. However, economic support that is targeted only at orphans can have a devastating impact, as it differentiates rather than integrates orphans from their social support networks (Foster & Williamson, 2000; Mann, 2002). The sheer scale of the pandemic testifies to the fact that nearly all children, not only those who are orphaned, will be directly or indirectly affected (UNICEF, 2001). Countries that have high rates of orphaning also have high levels of children seriously impacted by the pandemic (Hunter & Williamson, 2002). Therefore, a specific focus on vulnerable children as opposed to targeting orphans to the exclusion of other children is needed (Germann, 2003; USAID, 2004).

Unfortunately, policy and implementation are two different processes (Giese & Meintjes, 2003). It is in the application of policies that presents the real challenge. Malawi appears to be in the forefront in this regard since it has a national policy framework to protect orphans, guide provision of services, and define the roles of government and NGO's (Cook, 1998; Family Health International, 2001). Uganda, Thailand and Senegal have demonstrated that open committed leadership and political will are powerful mechanisms to address the needs of vulnerable children (Family Health International, 2001). The recently elected Kenyan government demonstrated their commitment to confronting the pandemic by acknowledging that nearly every family in Kenya is affected in some way by the ravages of HIV/AIDS (Lewis, 2003). The recently inaugurated president of Kenya appointed a HIV/AIDS cabinet committee with terms of reference that included prevention of HIV infection in schools, provision of ART, financial resources, orphaned children, stigma, the role of religious

communities, role of parliamentarians, the effects on women and children, the lifting of school fees and prevalence rates (ibid.). The abolition of all primary school fees led to 1,2 million children who had not been in school, enrolling within one week of the new policy. Kenya has an estimated 1,2 million AIDS-orphaned children. This is a striking co-incidence suggesting significant overlap between orphans and non-schooling children. However, simply abolishing school fees was insufficient. After school fees were abolished, the enrolment at one Kenyan school nearly doubled to five thousand, but when the headmistress insisted on the wearing of school uniforms, 2, 400 of these children again dropped out of school (ibid.). A statute dictating that school uniforms were unnecessary, led to children gradually re-enrolling. However, the stigma of having been publically discriminated against on the basis of being poor, made some children and their families reluctant to return to that school. The schools also needed vastly increased resources to cope with the growth increased enrolments figures since it is the quality of education that is so critical to sustain population stability and security. The Kenyan information ministry has made it compulsory to advertise HIV/AIDS information and prevention on all television and radio programmes (ibid.). The political will, as demonstrated in Kenya, may be the salvation for vulnerable children (Lewis, 2003). However, the impact and relevance of efforts made by the international community, governments, NGO's, and other entities is ultimately reflected in the extent to which they have made it easier for people to cope with the effects of HIV/AIDS (Atwood, 1997; Cook, 1998). Beyond the need for child-friendly policies and advocacy, attention needs to be given to improving the psychosocial quality of the patterns of microsystemic interactions.

6.2. Microsystemic Interventions: Psychosocial Support (PSS):

The profound and prolonged emotional and social suffering experienced by vulnerable children as they face complex and devastating adversities needs to be addressed at microsystemic levels (Levine & Foster, 1998). Psychosocial support (PSS) has been advocated as the strategy through which the ongoing psychological and social problems of individuals, families and communities can be identified and addressed (Germann & Mäddörin, 2002; WHO, 2003). PSS is an on-going process of meeting the physical, emotional, social, mental and spiritual needs of children, all of which are considered to be essential elements for meaningful and positive human development (Germann & Stally, 2003). The psychological element of PSS should create a sense in the child that someone cares about them enough to want to truly listen and understand their life story. When a child does not get the opportunity to express his or her feelings, their problems can increase and secondary

problems may emerge (Catholic AIDS Action, 2001). The social element ensures that children feel that they belong and are connected to a community. Through their social interactions, children come understand their life circumstances, can normalise and process their emotional turmoil, and realise that their autobiography has common themes with other children. The support element involves building children's resilience and creating the tools and personnel to support children (ibid.). It requires minimising the negative chain reactions associated with their life experiences and providing them with growth opportunities (Rutter, 1987), so that they cognitively and emotionally reframe their self image to the empowering one of being a survivor with many intrinsic talents and skills.

There is no doubt that the principles of PSS are the very principles that loving parents have been using for generations to raise their children. It is a concept with a short formal history and a long past in terms of its application. It is not new to communities. It is debatable as to whether PSS should be conceptualised as a microsystemic model or the overarching paradigm operative at all systemic spheres of influence. Hunter and Williamson's (2002) strategic framework would conceive PSS as being an integrated paradigmatic approach. The writer agrees with this position. However, for the purpose of this dissertation, PSS is considered to be largely microsystemic as it is primarily concerned with enhancing the quality of person-to-person interactions, as well as enhancing the caring-capacity of children's immediate environments. In essence, PSS assists people (adults and children) to cope with adversity and develop resilience (Germann & Stally, 2003).

The objectives for providing PSS vary according to individual, family, circumstance and time. They include increased emotional sensitivity and awareness along the following dimensions (Mädörin, 2003): (1) *The psychological dimension* is the intrapersonal realm reflected in increased self-awareness; the ability to identify and appropriately express feelings; enhanced self esteem; growth towards being better able to realise one's potential capacity; independence with regard to the ability to find direction and to be self-controlled. On the basis of traditional African culture (Mbambo & Msikinya, 2003) and trends in American popular literature (Covey, 1994), one could argue that interdependence would be the more beneficial outcome.(2) *The social or interpersonal dimension* is demonstrated by enhanced ability to understand and appreciate the feelings and thoughts of others; social responsibility in terms of increased co-operation and willingness to contribute as a constructive member of a group and improved interpersonal relationships.(3) *The support or adaptability dimension* requires increased capacity for problem-solving; reality-testing in terms of

assessing the correspondence between own experience and what objectively exists; and flexibility in terms of being able to adjust emotions, thoughts and behaviours according to the demands of changing situations and conditions. At the macrosystemic level, this refers to the establishment of comprehensive social support networks that link and coordinate existing psychosocial services with each other and with health, educational and social services to ensure effective use of resources.

There is a need to build community capacity to provide PSS in the form of counselling, support, activities, awareness and advocacy (Germann & Stally, 2003; Levine & Foster, 1998). At the microsystemic level, the objectives are for microsystemic interventions that (i) enable communities to mobilise to meet the needs of their vulnerable children, (ii) sensitise community members to the psychosocial needs of children in order to make the microsystemic interactions caring, supportive, empowering and rewarding for all concerned; (iii) build capacity to address past adversities and develop resilience and enhance coping; and (iv) draw people into collaborative partnerships to develop social support networks and mitigate against socio-economic impacts. Never before has there been such a need for individuals, families and communities to develop the trust, respect and collaboration (Phiri et al., 2001) required to offer co-ordinated holistic responses at the microsystemic level.

Very few intervention programmes have the ability or capacity to address the needs of the 'whole child' and to boost the capacity of the community to address children's needs (Hunter & Williamson, 2002). Synergistic programming and networking allows one to acknowledge one's own and others areas of strength and skill. From the perspective of a psychologist, the development of programmes that offer PSS to children, families and communities is both appealing and important. Existing psychosocial research has concentrated primarily on developed countries and even in these first world environments, the research has been limited to sick children and their families (Levine & Foster, 1998), or to offer IMCI (WHO, 2003). REPSSI has been in the forefront of advocating for PSS for children affected and infected by HIV/AIDS (Germann & Mäddörin, 2002; Germann & Stally, 2003; Think Tank, 2001).

6.2.1. PSS starting with community entry:

There are principles that guide community entry for research and intervention, especially when working with disempowered communities (Gasa, 1999; Meintjes, 2003). Developing credibility

within a community requires competent, confident and efficient field workers who demonstrate a willingness to become familiar with the local situation by becoming acquainted with the community's history, current context, assets and difficulties (Meintjes, 2003). Attentive and open-minded listening is likely to engender respect and co-operation (Collins, 1999; Meintjes, 2003). At structural and systemic levels, respect is communicated by the amount of control and decision-making power that community representatives hold and in how their varied concerns and suggestions are received and processed. Egan (1998) identified empathy and respect as core conditions for effective therapeutic intervention. Indeed, accurate empathy, genuine respect and compassion are the essential foundation of collaborative partnership for effective community work (Meintjes, 2003).

Community development work frequently takes place in small working groups of 15 to 30 participants (Duffy & Wong, 2002). Small groups facilitate active participation, the formation of collaborative partnerships and support networks, as well as the expression and containment of feelings and experiences. For small community groups to work effectively, there needs to be formal commitment to the strict adherence to a code of ethics, especially focussing on confidentiality, the applications and limits of which are carefully explained to participants (Killian et al., 2002).

Cognitive restructuring, as opposed to simple information dissemination, about the nature of HIV/AIDS can assist in decreasing the discrimination and stigmatisation experienced by PLWA. Constructive meaning can be created when community members express and debate their views, attitudes and beliefs and make suggestions about how best to cope as individuals and as a community (Phiri et al., 2001). Expressing views, ideas, emotions and myths can create a sense of common understanding, out of which shared and coordinated action can grow (Aggleton & Warwick, 2003).

Community spirit requires support, respect and development. It is necessary to know and respect the norms that are prevalent within a particular community (Super & Harkness, 1986), whilst acknowledging that most communities embrace a range of different cultural practices. Few individuals can be characterised as belonging to a single culture (Mbambo & Msikinya, 2003). Most people traverse cultures drawing on what seems most appropriate for the reality of their lives. For example, although many people in KwaZulu-Natal are Christians and attend church regularly, most still perform ceremonies honouring their ancestors, consult *sangomas*, hold a range of beliefs about the cosmos and what happens to the 'soul' at the time of death and thereafter. Christianity has

impacted on traditional African life and has been responsible for people abandoning traditional belief systems. However, it provides a strong spiritual anchor for many people.

Community entry is a sensitive process that needs to both demonstrate the application of the principles of PSS and requires sincere dedication to establish credibility and begin forming collaborative partnerships (Gasa, 2002; Meintjes, 2003). The above-mentioned elements, and others that are specific to particular contexts, need to be used to guide this delicate process.

6.2.2. PSS through the process of community mobilisation:

Community mobilisation is a key component of effective, sustainable interventions (Aggleton & Warwick, 2003; Family Health International, 2001; Phiri et al., 2001). Many communities have rallied to respond to the needs of children. "In the last decade, the response of communities in sub Saharan Africa has been nothing short of astounding ... thousands of these initiatives are organising their responses and moulding themselves into coordinated child support programs" (Phiri et al., 2001, p. 1). Some interventions are highly effective. Most lack a theoretical framework. Monitoring and evaluation, even in the form of careful documentation or reflection on the process, has often been lacking as many of the interventions have developed as a result of the mounting crisis (Aggleton & Warwick, 2003; Ntozi & Mukiza-Gapere, 1995; Subbaroa & Coury, 2003).

Community mobilisation is a process through which community members become aware of a shared concern or problem and with this awareness they decide to collectively take action to address the identified need and to create shared (as opposed to individual) benefits (Aggleton & Warwick, 2003; Mann, 2002; Phiri et al., 2001). Whilst the initial meetings may be facilitated by an external person or organisation, the momentum for the continued concern and commitment to the focus area must come from within the community group to facilitate sustainability (UNAIDS Best Practice Collection, 1997). With respect to vulnerable children, the characteristics of a mobilised community include community members who are (i) aware in a detailed and realistic way of individual and collective risks or vulnerabilities, so that certain children are identified as experiencing especially difficult lives (Killian et al., 2000); (ii) willing to acquire the practical knowledge and skills to meet the psychosocial needs of children (Aggleton & Warwick, 2003); (iii) motivated to offer PSS to vulnerable children, within their own capabilities, applying and investing their strengths and resources (such as time, energy, labour, etc.); (iv) able to participate in developing and implementing community-owned and driven initiatives to help vulnerable children and their communities, coupled

with an openness to evaluate the impact and take responsibility for successes and failures; (v) willing to seek external assistance and guidance when needed; (iv) actively encourage an ever-broadening representation and participation of community members and other key stakeholders; (vii) willing to build capacity and ensure sustainability by drawing on appropriate assistance; (viii) aware of the realities of the HIV/AIDS pandemic, yet are able to maintain hope, based on the value of collective community action (Subbaroa & Coury, 2003; UNAIDS Best Practice Collection, 1997).

In translating these ideals into action, Mann (2002) lists a broad range of activities that were undertaken by the COPE, Malawi Programme as integral to community mobilisation (only those that directly relate to the care of children will be included in the following listing): (i) identify and monitor orphans and other vulnerable individuals; (ii) organise structured recreational activities for children and young people; (iii) provide material assistance to orphans and AIDS patients living at home; (iv) HIV prevention activities such as drama groups for youth; (vi) develop community gardens to produce food and income to benefit vulnerable individuals; (vii) establish anti-AIDS clubs for children. A 1996 evaluation of this work indicated the success of these initiatives, so that staff were encouraged to focus attention on developing and helping to sustain these largely community-owned initiatives (Mann, 2002; Subbaroa & Coury, 2003). Although external people facilitated the initial impetus for the community to take action and to sustain effort, communities were assisted to take initiative and to provide an integrated response. In fact, many communities offered multi-sectoral programmes that included the five key elements of orphan-care, home-based care, youth involvement, prevention and community-resource mobilisation (Mann, 2002, p. 20). Synergistic programming was made possible through the functioning of multi-tiered committee systems at village, community and district level with strong technical and advisory support from national government (Cook, 1998; Mann, 2002; Subbaroa & Coury, 2003).

Starting a community effort is generally much easier than sustaining it (UNAIDS Best Practice Collection, 1997). Community initiatives require nurturance and reinforcement in order for them to have a meaningful impact. Scaling-up of effective programmes is essential in order to broaden the reach of the programmes (Germann & Mäddörin, 2001; Phiri et al., 2001). There is a large body of literature on how to mobilise communities (Aboagye-Kwarteng & Moodie, 1995; Aggleton & Warwick, 2003; Subbaroa & Coury, 2003). Most include a sequence of activities that describe needs assessments, developing plans, identifying and mobilising resources, implementing, and finally monitoring and evaluating (UNAIDS Best Practice Collection, 1997). Despite these clear manuals

on how-to-do-it in reality the dynamic nature of communities makes this an ideal that can seldom be realised (ibid.). There are several well-documented challenges to community participating and achieving a common goal: (i) Influential people - referred to as 'gate-keepers' or 'power-brokers' could hijack a process for their own political or other agendas; (ii) The time and energy that is expected from community members to serve as volunteers may be unrealistic when they themselves lead lives of extreme hardship, struggling on a daily basis to secure their own survival; (iii) pre-set expectations can fail to take into account the fluidity of this dynamic process; (iv) incomplete participation or representation; and (v) the need for external agencies to allow for a community's natural rhythms of everyday life. There is a need to empathise with the frustration, confusion and/or irritation experienced by people who work with highly stressed people (professional and/or volunteers) (UNAIDS Best Practice Collection, 1997).

The notions of community ownership and initiative require careful planning from the commencement of interaction with a community. The external agency must be sensitive to the limits to which a community is able to help itself in a non-patronising manner that facilitates access to information-rich resources and support. Additional energy can be cultivated through networking opportunities with others who are experiencing the same or similar problems, or with resource-enriching individuals or agencies (Germann & Mäddörin, 2002). It is necessary to give due recognition and affirmation to individuals who engage with community problems in a helpful manner. Formal, public recognition and celebration is well-deserved and meaningful for community participants (Mann, 2002).

In conducting community mobilisation processes in the partnering communities in the current study, a combination of principles and activities were used, as determined by the community members themselves, in accordance with participatory action research methodologies (Collins, 1999) (See Appendix B).

6.2.3. Sensitisation Programme [SP]:

Several child-focussed sensitisation and capacity building programmes have been developed in response to the distress experienced by volunteers who offer HBC (Germann & Stally, 2003). For example, community-based children's programmes, conducted by NGO's such as TREE, LETCEE, Sinani - the KwaZulu Natal programme for Survivors of Violence, Sinosizo Home Based Care Organisation, and The Valley Trust (all effective NGO's that operate in the KwaZulu Natal province

of South Africa) train community workers to work more effectively with children in distress. The community workers (employed or volunteer) who visit families engage at the coalface and directly witness the unfolding tragedy and the profound difficulties experienced by children affected by HIV/AIDS. They report feeling distressed and powerless, yet eager to learn ways to support the children (Schoeman et al., 2000).

The programme that is being evaluated in this dissertation was originally developed to meet the needs expressed by volunteers and staff working for the Sinosizo Home Based Care Organisation in Durban, South Africa. Working under the auspices of the Catholic Church, they had successfully rallied dedicated volunteers whom they had effectively trained in HBC. At their regular supervision, training and support meetings, the volunteers expressed concern for children who were witnessing the severe debilitation of parent figures and experiencing multiple family deaths. The Director of Sinosizo approached the Child and Family Centre at the University of Natal, Pietermaritzburg Campus, with the request that a training programme be developed to address these concerns. The first draft of the current sensitisation programme (Schoeman et al., 1999) was piloted, revised and again piloted using the staff and volunteers from the Sinosizo Home Based Care Organisation. The programme was well-received with the overall response being extremely positive (Killian et al., 2000). However, various difficulties with the original edition needed to be ironed out. The second draft (Killian et al., 2002) seemed to have effectively resolved some of the earlier difficulties, and although it remains a fluid and dynamic document, it was believed that a formal summative evaluation needed to be undertaken.

The major difficulty that had emerged from the piloting of the first edition was that whilst community members seemed to understand the need to develop warm and supportive relationships with vulnerable children, they tended to revert to their more familiar authoritarian approach and either instructed or ignored (although feeling highly compassionate) children when they returned to the field after the programme. Relatively few of the participants in the pilot programme changed their pattern of microsystemic interaction with children. These rigid patterns of interacting with children had been so habituated that it was difficult for many of the participants to change, to show their love and compassion, to be playful, and to actively listen without reverting to advice-giving, questioning, or giving of instructions. Community members expressed fears that if they were not firm with children, then the children would become difficult and disrespectful. In addition, for many the value of expressing feelings, and telling the story of one's life, was considered to be foreign and

potentially risky.

In order to overcome these difficulties, an apprenticeship model of capacity building with selected community volunteers was adopted (See Appendix D). It was assumed that if volunteers and professionals joined forces, they could learn from each other: (i) apprentice-facilitators would observe, participate and acquire the skills necessary to both work therapeutically with children and to conduct the structured group therapy programme (SGTP), thereby becoming more child-centred, less authoritarian and more therapeutic in their interactions with children; (ii) the psychologists would be able to work with apprentice-facilitators to gain important information about the customs and traditions within the community and culture; (iii) the children would benefit by having members of their own community who had insight into their difficulties and who could form a social support network for them, when the psychologists were not available. It had originally been thought that the apprentice-facilitators would also be able to translate. However, in most circumstances it became necessary to separate out these roles, in order to free the apprentice-facilitators to be more spontaneous with the children. The SP (Killian et al., 2002) therefore became an integral part of the process through which this community-based intervention could meet the psychosocial needs of children. After entering and mobilising a community, 25 to 30 volunteers were identified by community members to participate in the SP. The specific aims and objectives of the SP are set out in Table 6.1. This 5-day programme covered the topics in Table 6.2, using a participatory methodology, based on the principles of adult education. Formative assessments took place at the end of each day and three forms of summative assessments were undertaken.

A brief overview of the SP will now be presented. Each day began with a prayer or hymn that was led by a volunteer community member. An energising ice-breaker prepared the group members for the day's proceedings. Energisers and new games were used extensively throughout the programme and were particularly well-received by the participants. The first day's work schedule began with a brief introduction or go-around to reinforce the important contribution that each individual had on the overall success of the programme. The purpose was to convey a sense that the group consisted of a number of individuals each of whom was significant in terms of the overall functioning of the SP group and within the community as a whole. For many individuals, it was an unfamiliar experience to have to speak in front of a group and much support was offered to encourage people to speak-up in front of the group to report on how they were feeling or what they had done, thought

or worried about on the previous evening.

Table 6.1: Aims and objectives of the sensitisation programme:

	Participants as Individuals	Participants as Community
Empowerment	<ul style="list-style-type: none"> • Self confidence • Faith in own capacity to help and one's own knowledge base • Motivation to apply experience for own benefit as individual and family member • Willingness to ask for help and support when needed 	<ul style="list-style-type: none"> • Confidence to participate in community decision making • Willingness to advocate for vulnerable children • Ability to speak about HIV/AIDS • De-stigmatise HIV/AIDS and work against discrimination
Knowledge	<ul style="list-style-type: none"> • Awareness that one learn's from own experiences • Holistic understanding of vulnerable children's needs - physical, social, educational, emotional and spiritual • Understand the impact of risk • Identify indicators to distress • Ways of building resilience and adaptive coping • PSS is critically important and does not cost much in financial terms • Impact of this work on self and need for self care • Resilience building techniques • Memory boxes are for everyone 	<ul style="list-style-type: none"> • Holistic understanding of the community through the community profiles • Understanding of how some communities become vulnerable • It takes a village to raise a child • PSS applies to individuals, families and communities • Active advocacy for vulnerable children • Agricultural and income generating projects • Importance of feeling part of a community • Ability to critically reflect on cultural norms and customs and their implications for children.
Skills	<ul style="list-style-type: none"> • How to communicate with children • Basic counselling skills - active listening & reflecting feelings • How to talk to children about death • Bereavement counselling • Helping starts at home and with self 	<ul style="list-style-type: none"> • Organising and implementing activities and support for vulnerable children • Importance of record keeping and group work • Acquiring social services

Similar programmes have been written in many African countries, with marked similarities in content, although invariably the emphasis differs in each circumstances (Cook, 1998; Mäddörin, 2000; PACT, 2002; SANTSEP, 1999; SCOPE & Family Health International, 2001). As far as is known, few formal evaluations have been conducted on them. Rather, most have successfully met their purpose and are regarded by the participants and recipients as useful. REPSSI has embarked on a process of collating a synthesised training programme that will draw these resources together and share the significant learnings across the various organisations that offer PSS to children in the sub-Saharan African region (Germann & Stally, 2003). The researcher is involved in this process and this

research programme will inform some aspects of REPSSI's work.

6.2.4. PSS through structured group psychotherapy with vulnerable children:

Throughout history children have functioned within the context of groups - siblings, peers, school, play groups, sports, etc. Many of these groups are normal powerful socialisation agents (Slee & Shute, 2003). The risk and resilience literature indicates that children who do not have well-established social support systems are at increased risk, and the presence of such networks operates as a resilience enhancing variable. Groups provide children with real-life opportunities to establish growth-promoting social interactions and counter-balance the detrimental impact of unstable adult support systems, such as those that are likely to characterise the lives of vulnerable children.

The inherently social nature of human beings makes group therapy an imminently suitable and powerful therapeutic modality for working with children (Wenar, 1994). This is especially so on the African continent where there is a richly communal focus. Children frequently manifest psychological distress through either withdrawal or maladaptive behaviour within their peer networks (Wenar, 1994). They benefit from interventions that directly address peer group interrelationships (Kymiss, 1996). In fact, group psychotherapy can be regarded as a treatment modality of choice that has effectively been used to help children deal with emotional, behavioural and social problems in many different settings (Kymiss, 1996; Wenar, 1994). It seems a particularly appropriate intervention strategy for those who may have suffered social exclusion or discrimination.

Much of the theoretical consolidation in the field of group psychotherapy is based on the seminal work by Yalom (1985). Group interventions have clear advantages in terms of their curative capacities (Yalom, 1985). He believed in the power of the group, as opposed to the power of the therapist, so advised therapists to adopt active, supportive roles in facilitating the group process and to de-emphasise intrapsychic or transference phenomena (Rosenbaum & Patterson, 1995). One of the consequences of Yalom's contribution was an awareness that a variety of community mental health workers could be successfully trained to facilitate group therapy (1985). The literature focus also shifted towards advocating integrative models of group therapy that were time-limited and structured (Kymiss, 1996; Rosenbaum & Patterson, 1995).

Groups are *microcosms of society* that expose participants to parallel examples of their broader interpersonal environment. They simulate aspects of the wider world and provide opportunities to give

and receive interpersonal input (ibid.). Thus, group therapy can be a powerful mechanism for growth, healing and change. Using a variety of qualitative techniques, Yalom (1985) identified the effective ingredients of group therapy and applied them in his integrative model of interpersonal therapy. He concluded that there were three main factors that were instrumental in increasing the therapeutic impact of groups: (i) interpersonal input; (ii) catharsis; and (iii) self-understanding (Rosenbaum & Patterson, 1995):

1. Interpersonal input: Social learning, in the form of interacting and observing, is a key mechanism for socialisation especially in the absence of adult attachment figures (or when the attachment relationships are compromised). Groups provide children with:

- feedback about behaviours that are annoying or pleasing to others. As such, it provides guidance on how to adaptively interact with others and can give insight into those cognitions that are self-defeating or self-enhancing (Rose & Edleson, 1987).
- a safe and accepting space to experiment with new skills and behaviours (Berkovitz, 1987a). Groups can become places where children can reach out to others for support especially if they have previously felt that others would not be able to understand them or if they are ashamed, embarrassed, lack trust or feel guilty as a result of their negative life experiences.
- the experience of feeling less marginalised and to normalise their experiences (LeCroy & Rose, 1986). In turn this enables them to feel a sense of shared reality, group cohesion, a sense of belonging and universality (Yalom, 1985). It can break down the feelings of isolation and alienation frequently experienced by people who have been stigmatised or have suffered significant emotional crises. Feeling accepted is often a first step towards establishing the relationships that are especially important in developing resilience (Mallman, 2002; Mäddörin, 2000).
- enable children to learn appropriate interaction with their peers. In this way, they are likely to be reciprocally reinforced, thereby setting in motion cycles of social interchange with the potential for appropriate socialisation and peer acceptance (Geldhard & Geldhard, 2000).
- opportunities for altruism, whereby children become aware of their own and other's feelings, experience compassion and understanding, paving the way towards proactivity (Yalom, 1985). This can also instill hope in children whose lives have seemed to be bleak and isolated.

2. Catharsis: The opportunity to *identify and express emotions* is an important curative element of group therapy (ibid.). Participating in group therapy creates opportunities for emotional expression within a safe and contained space (Wenar, 1994; Winnicott, 1965). When one expresses feelings and

thoughts, the intrapsychic need to defend against extremely powerful emotions is unlocked (Winnicott, 1965) and one feels relieved, understood and accepted. The therapeutic support and encouragement enables the child to become self aware rather than reactive to a hostile environment (Geldhard & Geldhard, 2000). Traditional Black African cultures have mourning and funeral rituals that tend to exclude children in the belief that this would 'protect' them from the grief associated with the loss of loved ones. Seldom is a child given an explanation about what has happened when someone has died (Marcus, 2002). Unfortunately, this denies them the opportunity to clarify what has happened, to express their emotions and to be included as part of the inner circle of people considered to be most directly affected by the death. Group therapy affords them the opportunity to express and process their grief within a containing environment in an atmosphere of support and care.

3. Self-understanding: Groups provide opportunities for restructuring cognitions that may have arisen from other person-to-person interactions (Wenar, 1994). Children are inclined to experience feelings of guilt, confusion, fear, internalised badness, inaccurately applied transductive reasoning, etc. These immature cognitions can be corrected within the group and through social learning. Through group interactions, people make the reassuring discovery that others share similar feelings and experiences to themselves (Wenar, 1994, p. 496). As self-understanding improves, self esteem increases (Wenar, 1994). They have opportunities to try out new forms of social functioning and increase their range of peer interactions.

Working in the context of a group has the advantage of both limiting the special relationship that frequently develops between a client and individual therapist, while simultaneously facilitating the development of caring relationships between the group participants and the community-volunteers who become apprentice-facilitators. Given the demographic profile of the HIV/AIDS pandemic, many children lack consistent and stable care from primary caregivers. Working in peer groups, decreases the possibility of dependency developing between the children and the therapist as well as increasing the possibility that a lasting and supportive relationship will be forged between the children themselves, and between them and the volunteers, especially the apprentice-facilitators. The cost effectiveness of attending simultaneously to several children's psychosocial needs is often given as an advantage of group therapy. In this instance, it is believed that group intervention embodied within a community development model is the *treatment of choice*. Co-incidentally the magnitude

of the pandemic, as well as the lack of human and financial resources, render individual interventions inappropriate from an economic perspective.

The Structured Group Therapy Programme (SGTP) used in this research programme is an adaptation of the Humuliza Model from Tanzania - a model declared to be best practice (UNAIDS, 2001). From a theoretical perspective, it is based on an integrative, structured model that is topic-focussed. It is designed for specific sub groups of children, at compatible developmental levels, who have similar characteristics and experiences, and thus are assumed to have similar needs (Geldhard & Geldhard, 2001). The Humuliza Model (Mädörin, 2000) was adapted by the writer (Killian, 2002) in three ways:

- **Supervision:** The SGTP was recognised as having the critically important potential to evoke powerful emotions in children who had experienced major adversity. Likewise, the therapists and apprentice facilitators were likely to experience much distress when they listened to the life stories and saw the emotions of the children. Yet, the SGTP had great appeal especially for community workers due to the structured nature of the sessions, its availability on the internet (URL: http://www.repssi.org/programs_frame.htm) and its potential to meet an urgent need to help vulnerable children. The programme was thus adapted to emphasise and enhance the understanding of the various processes and to emphasise the critical role that supervision plays in working with deep emotions in a therapeutic manner. Therefore, supervision and debriefing after each session became critical to both help apprentice facilitators (i) to debrief and (ii) to develop a therapeutic understanding of children. The apprentice facilitator aspect of the programme was intended to build the capacity of key community volunteers to address the psychosocial needs of children using a psychotherapeutic model, but also to demonstrate the impact of a PSS approach in working with children. As far as the children were concerned, it was hoped that this would broaden their exposure to caring adults and give them the experience that external support systems are there for them. Hopefully, this would encourage them to look for and use these support systems. By enhancing the sensitivity of community members and key stakeholders to the psychosocial needs of children affected by HIV/AIDS, as well as the needs of the many vulnerable children living within poverty stricken communities. It was also envisaged that community members and the children would become strong advocates for the needs and rights of children within the partnering communities.

- **Indigenous games:** When Dr. Mădörin wrote the programme, he showed great insight into children's needs to simply have fun and play games. Whilst some of the games that are incorporated into the programme are of cross-cultural applicability, he also adapted games to be non-competitive and of the 'new games' genre. The rationale was to anchor learning from working sessions during the group sessions. It was hoped that by using cultural games, children would become proud of and familiar with traditional and appropriate cultural practices, games, songs, myths and legends. This could enable them to develop a strong sense of group identity, with knowledge about the origins and meaning of cultural practices.

The researcher believed that some indigenous games could be adapted for use within the therapy sessions. Therefore, while conducting community entry and community mobilisation processes she collated descriptions of indigenous games. There were three main sources of this information: grandmothers, young mothers and creche workers, and community workers from Sinani, KwaZulu Natal Programme for Survivors of Violence. Many of these games involve song. The community members usually led the song and games with great enthusiasm and excitement while children played. They were often only able to recall the details of how to play games when there was a group to collate the rules. The apprentice facilitators played a vital role in leading these games during the programmes.

- **Some minor alterations** were made largely to make the processes more suitable for *isiZulu* children, to enrich the psychological meaning of certain activities, and to make better use of time allotments.

The Structured Group Therapy Model [SGTP] (Killian, 2002) has 15 pre-defined sessions covering two broad themes: (i) *Looking back* into the children's past experiences to deal with emotional turmoil, loss, grief, stigma and discrimination with the aim of them gaining some sense of mastery over their past experiences; and (ii) *Looking forward* to develop greater resilience by enhancing self esteem, enabling more adaptive coping and enabling them to access appropriate support when they need it (See Appendix E). Although risk and resilience are in some ways integrally related, it was useful in this programme to divide these into distinct stages of the intervention.

Children benefit from having routines in their world, as it is through the use of routines that the world becomes a predictable and safe place (Mallman, 2002). Vulnerable children frequently loose

daily structure as things change and the future becomes unpredictable. Therefore, there was a routine within each session to help establish the therapeutic frame. The daily routine consisted of 7 sections: (i) the starting ritual; (ii) an introduction to the day's theme; (iii) the first work unit; (iv) break & refreshments; (v) the second work unit; (vi) indigenous games; and (vii) the closing ritual. At the end of each session, there was a group supervision session with the psychologist and apprentice-facilitators. This provided an opportunity to think about what happened, talk about any issues that had affected them personally, discuss the things that went well and that did not work effectively, raise concerns about individual children and plan for the next session. In effect the supervision sessions can partially be regarded as formative assessments, since it was frequently necessary to use the information from one supervision session to guide the next group therapy session with the children.

In general, the purpose of the SGTP was to introduce a stabilising element into the children's lives to counteract the emotional chaos caused by actual and/or imminent loss of a loved one, or other vulnerability variables, through structuring the daily sessions. It was anticipated that this would decrease the emotional distress that may be exhibited through the manifestation of clinical symptoms such as those associated with internalised and/or externalised disorders (Killian & Brakarsh, 2004) and increase their self esteem. It would also increase the number and quality of social support networks available to vulnerable children.

It was believed that this community-based intervention offers a means of enhancing the quality of microsystemic interactions that vulnerable children experience. It operationalises strategies 1,2 and 3 of strategic framework that was endorsed by the international role players in this field (Hunter & Williamson, 2002). By sensitising community members to the psychosocial needs of vulnerable children, and using an apprenticeship model to apply the principles through the SGTP, children and communities would be strengthened. Community members would be willing to embark on their own initiatives to meet children's needs with a specific focus on their psychosocial needs. This programme asks community members to give their love and time to address the psychosocial needs of vulnerable children. It was anticipated that by ameliorating risk factors, one would be able to enhance resilience, by focussing on the macrosystemic interactions that were most likely to have a direct impact on the day-to-day functioning of the children.

Chapter 7

Methodology

The HIV/AIDS pandemic has thrown the medical and social sciences into crises, as professionals and the lay public struggle to understand, prevent and intervene in the immense human suffering that is being wrought on the world's most vulnerable population groups. It indisputably qualifies as a situation in which rigorous programme evaluation is critically important. It can be considered to be primarily a social phenomenon arising from a disease that gives rise to diverse behavioural, psychological and social consequences (Richter, van Rooyen, Solomon, Griesel, & Durrheim, 2001). The focus of this research programme is on a particularly vulnerable group as it considers the psychosocial consequences of the pandemic on children and the communities in which they live.

The objective was to develop an effective method of operationalising three of the strategic principles that had been identified by international aid organisations as necessary components of intervention programmes for children affected by HIV/AIDS (Hunter & Williamson, 2002). The first three components of the strategic framework operate at a microsystemic level and emphasise the need to strengthen, mobilise and support children, families and communities (ibid.). On the basis of these principles, the researcher focussed on developing an intervention programme through which PSS could be offered to vulnerable children, whilst simultaneously acknowledging that children need social systems (with a focus on community rather than family) to help and support them. The core objective was thus to develop an intervention to enhance the quality of microsystemic interactions, by facilitating the provision of PSS to ameliorate risk, to strengthen and enhance coping and to build resilience and strength in children and communities.

The multifaceted nature of the problem called for a multi-tiered community-based intervention. The intervention programme, in its entirety, consists of five stages: (i) forming partnerships with communities; (ii) community mobilisation on the needs of vulnerable children; (iii) a sensitisation programme (SP) for adult community members on the psychosocial needs of vulnerable children; (iv) a structured group therapy programme (SGTP) for vulnerable children; and (v) on-going support and capacity building. Of these five components, two were evaluated for the purpose of this dissertation: (i) the 5-day sensitisation programme (SP); and (ii) a 15-session structured group therapy programme for vulnerable children (SGTP). The limited financial and personnel resources that are available to meet the burgeoning needs created by the HIV/AIDS pandemic mandates that precise and accurate appraisals of intervention programmes be conducted (Foster & Williamson, 2000). So, the purpose

of this research programme was to provide information about the effectiveness of these two components in terms of their strengthening and supporting capacities.

7.1. The research ethic:

The concepts of strengthening, mobilising and supporting imply the need for an ethic that embraces participation, collaboration, involvement and partnership-building between researchers and those who experience the problems at grass roots and so know first-hand the need for change and for finding solutions (Robson, 2002). Action research explicitly and purposefully is an integral part of the change process as it engages people in studying and solving their own problems (Whyte, 1989, in Patton, 1990). It was therefore fundamentally important that all interactions between the researcher and the communities/children was based on this specific ethic.

Participatory action research (Bhana, 2002) provides a means of ensuring that the focus remains one of strengthening and supporting the participants. Integral to the implementation of the entire programme was a mode of working that prioritised the formation of collaborative working partnerships between the researcher and the community members. Participatory action research (PAR) is essentially about “democratising the knowledge-making process” (Bhana, 2002, p. 230), as there is communal participation in the process of knowledge creation, that in turn facilitates empowerment. Hoshmand and O’Byrne (1996, in Bhana, 2002) argue that knowledge of people and their social contexts can only be gained when change is attempted and authentic change can only occur when there is an attendant shift in the knowledge-base of those involved. The principle of trying to know *with* others, as opposed to knowing *about* them (Bhana, 2002) is fundamental to PAR and has the benefit of creating egalitarian relationships that nurture respect and empowerment.

The researcher recognised a strong connection between the concepts of strengthening, supporting and mobilising (Hunter & Williamson, 2002) on the one hand, and the concept of empowerment on the other (Shapiro, 1999). An ethic of collaboration was adopted to facilitate a process in which people felt meaningfully affirmed, involved, accepted and valued - all essential components of empowerment. Therefore, the primary desired outcome of the intervention was growth in self-esteem in the participants combined with greater confidence in their own pre-existing knowledge bases. The desired outcome would be the creation of an atmosphere in which the research would cease to be a marginal activity (van der Eyken, 1992) and the researcher would be considered peripheral to community-owned and -driven initiatives that offered PSS to vulnerable children. There was an explicit intention that the research and the intervention would serve as mechanisms to pull people

together to form strong intra- and inter-community support networks. Community mobilisation, sensitisation, empowerment and skills-transfer are all processes that aspire to strengthen communities by enlisting the involvement and commitment of community members, generating a shared knowledge base and developing capacity.

7.2. Rationale for this research programme:

A proliferation of community-based initiatives (Phiri et al., 2000) have been developed in response to the HIV/AIDS crisis. However, it is believed that many programmes have (i) not been informed by theories of child and/or community development; (ii) are piecemeal and fragmented in nature, consequently they fail to take into account the holistic and complex relationships between the child, the community and the problems brought about by the HIV/AIDS pandemic and other adversities; and (iii) have not been evaluated for their effectiveness. This research programme evaluated two components of a community-based intervention that aimed to meet the psychosocial needs of children who have been exposed to a multiplicity of risk factors, including those posed by the HIV/AIDS pandemic. The theoretical base acknowledged the risk and resilience literature with respect to an awareness that their life circumstances render many of the children highly vulnerable, with a statistical probability of a dismal future (Germann & Mäddörin, 2002; Schönteich, 2002). An awareness of the social ecology of childhood indicated the need for the intervention to target various systemic levels of a child's life, in order for the intervention to be effective.

The objective of the research study was to (i) determine the effectiveness of the programme; (ii) identify ways of improving the programme; and (iii) solve specific problems at community level. The goal was to identify ways in which children and communities could be strengthened to deal more adequately with the adversities that they face and to consider if the intervention was worthy of up-scaling to other contexts. "Purpose is the controlling force in research" (Patton, 1990, p. 150) and since there were three major purposes it was necessary to conduct three types of analyses, using different research typologies in order to service the various purposes (See Table 7.1):

- **Summative evaluation** procedures were adopted to judge the effectiveness (Patton, 1990) of the two intervention programmes - the Sensitisation Programme (SP) that was aimed at a community level of intervention and the Structured Group Therapy Programme (SGTP) that aimed to meet the psychosocial needs of vulnerable children living within high prevalence HIV/AIDS communities.
- **Formative evaluation** enabled the programmes to (i) be adapted in an ethical manner to respond to the needs of specific participants of both the community and child interventions;

Table 7.1. An overview of the research programme:

Units of Analysis	Overarching Research Questions	Applicable Design	Methodologies
Communities with high HIV/AIDS prevalence rates	<ul style="list-style-type: none"> * Is the SP effective? * Is the SP more effective in different geographic regions and forms of communities? * Does the community effectively offer PSS to vulnerable children? 	Summative evaluation	<ul style="list-style-type: none"> * Focus group discussions * Post SP evaluation questionnaires * Community profiles * Community initiatives
	<ul style="list-style-type: none"> * Are there ways in which the programme can be improved? 	Formative evaluation	<ul style="list-style-type: none"> * Daily evaluations (Little research focus)
	<ul style="list-style-type: none"> * Form collaborative partnership to strengthen the communities. * Develop working definitions and make explicit the assumptions held about key concepts. 	Action research	<ul style="list-style-type: none"> * Community selection, mobilisation, SP and on-going support and follow-up * Community-based conceptualisations of key concepts.
Vulnerable children resident in these communities	<ul style="list-style-type: none"> * What is the psychosocial profile of manifest symptoms of vulnerable children? * Is the SGTP effective in ameliorating symptoms and enhancing resilience? * Does the programme work more effectively with certain subgroups: gender, age and geographic region. 	Summative evaluation	<ul style="list-style-type: none"> * 4- way factorial quasi-experimental design, using child, educator and primary-caregiver questionnaires.
	<ul style="list-style-type: none"> * Are there ways in which the programme can be improved? * Does the apprenticeship model of capacity building work effectively? 	Formative evaluation	<ul style="list-style-type: none"> * Supervision after each session and training workshops
	<ul style="list-style-type: none"> * Can trained community members accurately identify vulnerable children? * Can trained community members acquire the skills to conduct the SGTP, using an apprenticeship model of training. 	Action research	<ul style="list-style-type: none"> * On-going participative workshops and supervision.

SP = Sensitisation Programme; SGTP = Structured Group Therapy Programme; PSS = Psychosocial Support; CMM's = Community mobilisation meetings.

- and (ii) to obtain ideas about how to improve the programmes (Patton, 1990) in terms of better meeting the psychosocial needs of the children and their communities.
- *Action research* facilitated processes whereby communities could be mobilised, their knowledge harnessed, their confidence enhanced and resources developed. It also provided the opportunity for the community members to collectively make explicit their conceptualisations of key concepts involved in the SP and in offering PSS. Empowerment was a basic aim in this regard.

7.3. The research questions:

The research programme determined whether two of the components of the community-based intervention programme (the SP and SGTP) effectively offered PSS to vulnerable children living in high prevalence HIV/AIDS communities, according to the research questions set out below. The specific hypotheses, accompanied by detailed descriptions of the methodologies, will be presented in Sections 4 (the SP) and 5 (the SGTP).

7.3.1. The first unit of analysis: Evaluation of the community-based variables:

Summative evaluation:

- Does the SP effectively sensitise participants to the PSS needs of vulnerable children? Additionally, does the SP empower community members to offer PSS to vulnerable children?
- Does the SP work more effectively in certain geographic regions? KwaZulu Natal (the province in South Africa, where this research took place) has a high population density, especially within rural areas, as well as high HIV incidence (Shisana & Simbayi, 2002). One of the aims was to assess if the programmes' effectiveness would vary according to participants' geographic regions (rural, peri-urban, township and informal settlement).
- Having attended the SP, are the participants motivated and able to offer PSS activities to the vulnerable children in their communities.

Formative evaluation:

- Are there ways in which the SP can be improved? This was not a specific focus since the summative evaluation was the primary objective. However, in conducting a programme one always systematically seeks ways of improving.

Action Research:

- Can the researcher and community members work in collaborative partnership to strengthen capacity to meet the psychosocial needs of vulnerable children?

- How are key concepts conceptualised by community members: health, illness, death, community, orphans and vulnerable children and PSS? Developing an understanding of the way in which communities define these key concepts was regarded as an essential aspect of the programme. The information gained in this regard was used to generate specific focus areas and to develop working definitions.

7.3.2. Second unit of analysis: Vulnerable children:

Summative evaluation:

- What is the psychosocial profile of manifest symptoms in vulnerable children and orphans?¹
- Is the SGTP effective in ameliorating symptoms and enhancing resilience?
- Does the SGTP work more effectively with certain subgroups, in terms of gender, age, geographic region, or nature of adversity?

Formative evaluation:

- Are there ways in which the programme can be improved to more effectively address the psychosocial needs of children in the target communities?

Action research:

- Can trained community members reliably identify vulnerable children?
- Can trained community members acquire the skills to conduct the SGTP, using an apprenticeship model of training.

The **major focus** of this research programme lies in the summative evaluation of the SP and the SGTP. The interrelationships of the various components of the intervention programme required an evaluation that acknowledged the inter-connection between the different components. Action and formative research needed to be undertaken to achieve the objectives of the two main components of the intervention programmes.

Establishing the effectiveness of the programme was considered to be a pre-requisite before investigating the impact, sustainability and cost-effectiveness of the intervention. These important concerns were regarded as falling outside the scope of this research programme. Time and resource constraints precluded an evaluation of: (i) impact - durable changes that are effected during an intervention, (ii) sustainability - energy that is likely to be maintained over time, when external resources are withdrawn, and (iii) cost-effectiveness in terms of comparing the results with the

¹Although this a descriptive analysis, it forms the basis on which the summative evaluation was made and it provided useful comparative data.

financial, human, time and material resources that are needed in order to achieve the objectives (Shapiro, 1999, p. 6).

7.4. An overview of the programme: matching research typology with intervention:

A brief résumé of the entire process will be presented in this section (See Table 7.2), to enable the reader to gain insight into the multi-faceted nature of this intervention programme that called for careful matching of research typologies with the various steps in implementation and evaluation.

Table 7.2: A Brief résumé of the procedural stages

Stage	Procedure	Main outcome measures
1	Community selection	Identification of nine partnering communities: three rural, township and peri-urban areas. Informal settlements were excluded from this study.
2	Community entry & mobilisation	Formation of collaborative partnerships between researcher, key stakeholders and community members to mobilise on the psychosocial needs of vulnerable children (Protocol in Appendix B).
3	Sensitisation programme (SP)	20 - 30 adult community members participate in SP (identification of participants and logistics undertaken by community). Formative and summative evaluation.
4	Community-based initiatives	Community identify vulnerable children and begin offering PSS. Building and reinforcement of social networks within the community. Support and encouragement offered by researcher.
5	Baseline data collected	Community members trained in basic research methods and then collect the pre-intervention data. Children randomly assigned to experimental or control conditions in 7 of the partnering communities.
6	Experimental and Control Interventions.	Groups of 12 - 18 children in two age groups (8-10 years and 10-12 years) participate in various experimental and control conditions.
7	Analysis of Data	Thematic analysis of evaluation data on the SP using post-workshop evaluation forms, focus groups and community initiatives. 4 way-factorial statistical analysis to evaluate the effectiveness of the SGTP.
8	Intervention with control groups	Conduct SGTP with control groups. Opportunity for increasing the capacity of apprentice-facilitators to conduct the SGTP. Continue to involve all the vulnerable children in a variety of community-based initiatives.
9	On-going support of PSS activities	On-going support and encouragement offered to the partnering communities to continue to offer vulnerable children a variety of PSS community-based initiatives.
10	Dissemination of results	Dissemination of the programme as a model for community-based intervention with vulnerable children in high HIV/AIDS communities.

Applying the principles of PAR, the programme began with community selection, entry and mobilisation. The process of selecting the partnering communities was a complex process that needed

to ensure that partner communities fulfilled certain criteria (See Section 7.5). Having identified potential partnering communities, the process of community entry and mobilisation proceeded. The intention was to facilitate a process through which the community would recognise, own and commit to addressing the psychosocial difficulties experienced by their vulnerable children. Attempts were made to ensure participation of all major stakeholders such as local traditional and political leadership, people who work with children in the partnering communities (educators, social workers, community mental health workers, home-based care volunteers), FBO, NGO and CBO representatives, youth, PLWA and affected families and children. A series of community mobilisation meetings (CMM's) were conducted in each community, with many community members participating in more than one CMM's (See Appendix B for the schedule of CMM's).

Having a pre-defined problem focus at the time of community entry may seem to be at odds with PAR. The principles of action research required that collaborative relationships be formed to explore if a problem existed and how the problem was to be framed and addressed (Bhana, 2002; Collins, 1999). In practice, most communities (See Section 7.5.1. for discussion of the exceptions) readily recognised the pervasiveness and severity of risk and adversity that some children in their communities were experiencing. Employing the principles of action research led to each community having its own specific focus and the process of entry and mobilisation was unique to each community. The documentation of community entry and mobilisation is considered to be outside the focus of this dissertation, however, the researcher developed a community entry and mobilisation protocol that proved to be useful in expediting this critical process (See Appendix B).

During the CMM's and subsequent dialogue, there was much debate on the concepts of vulnerability and psychosocial needs. Neither of these terms translate neatly into *isiZulu* (the home language of the participants) but the depth of understanding gained by both parties in terms of these key concepts was invaluable. In poverty-stricken communities in which basic survival needs are not guaranteed and in which there is no food security, some individuals regarded concern about psychosocial development as a luxury that they could not afford. The validity of this perspective is obvious and became a focus for independent initiatives undertaken by community members. These included establishing community food gardens, income generating projects, collective action to obtain documents for registering births and obtaining social grants, and so forth. Clearly these were valuable contributions towards meeting the needs of children.

Although the researcher hoped that one of the outcomes of the community entry and mobilisation

would be a request for adult community members to participate in training/sensitisation workshops on PSS, she waited until the request was made by community members. The rationale in this respect was for the community to recognise and use their own resources first. In all but two of the communities (both extremely under-resourced rural communities), the request for specific input on PSS took place several months after the community had begun their own initiatives. Once a request for a workshop was made, the 5-day SP was offered. Community members were asked to identify a group of 20-30 interested and committed people, find a suitable venue (community hall, church, school or tribal court) and make all of the logistical arrangements. The researcher took responsibility for providing catering and training materials.

Up to this stage, action research had been the research/intervention typology, since the purpose had been to generate immediate action to solve problems, in the belief that people can solve problems by themselves (Patton, 1990; Robson, 2002). The focus of the intervention was on the communities' strengths and problems, with no desire to achieve generalisability (Robson, 2002; Silverman, 2000) beyond establishing broad protocols. Once the SP was initiated, the work continued to be informed by a PAR ethic, but the research focus shifted to formative evaluation. The purpose in this regard was to focus on the 'here and now' needs of the participants and to identify the strengths and weaknesses of the SP. The assumption was that people can and will use information to improve what they are doing (Patton, 1990). However, using formative and action research means that the desired level of generalisability remained relatively limited (Silverman, 2000).

The first phase of the summative evaluation of the SP was undertaken on the final day of the SP. Research participants were requested to develop plans of action through which they would offer (or strengthen since some communities had pre-existing activities) PSS to vulnerable children. These community initiatives generated one of the measures of the effectiveness of the SP. The SP participants were asked to complete post-workshop evaluation forms. In addition, at one of the follow-up support meetings, three people from each community were randomly selected to participate in a focus group discussion that was conducted by an independent researcher.

Follow-up support meetings were then arranged to support the SP participants in carrying out their plans of action. The communities took on the responsibility of organising activities that offered PSS to vulnerable children. At these meetings, participants reported on their volunteer work offering PSS to vulnerable children in their community. The researcher's role was to give support, guidance and input if necessary.

In all but two of the communities, the participants decided on the need to form a register of vulnerable children in their areas. In the other two communities where this was not a spontaneous suggestion, the researcher indicated that some of the other communities had found this to be useful and the decision was made to also collate registers in their areas. During the SP, working definitions of risk and vulnerability had been developed. The community members used these definitions to identify vulnerable children largely on the basis that some children were experiencing especially 'difficult lives'. Communities made no distinction between children rendered vulnerable through the HIV/AIDS pandemic and other risk factors. The process of establishing a register of vulnerable children was in itself a community awareness-raising exercise that enabled the reality of some children's life experiences to be clarified and explored. Training in ethical procedures was offered to ensure that this was done in a proper and responsible manner. The collating of registers of vulnerable children served as a major impetus towards people taking action on behalf of vulnerable children both in terms of advocacy and in more practical terms such as assistance to obtain social welfare, gain admission to school and so forth, as well as in offering PSS.

At this stage, the researcher offered to conduct the 15-session structured group therapy programme (SGTP) with children in the 8 - 12 age range. The help and support of selected community members was solicited so that they would be exposed to a therapeutic, child-centered manner of relating to children and be apprenticed to facilitate SGTP. In each instance, the primary facilitator of the SGTP was a qualified psychologist who took ethical and legal responsibility for the well-being of the children.

UNAIDS (2001) endorsed the original form of the SGTP (Mädörin, 2000) as a best practice model and pilot administrations of a modified version of this programme (Killian, 2002) had been promising. The modifications had been undertaken by the researcher to include (i) indigenous games, (ii) culturally matched stories, names, songs and activities, and (iii) greater focus on vulnerability as opposed to orphanhood. This modified version of the SGTP was evaluated for its effectiveness in the positivist tradition (Potter, 1999; Shaprio, 1999), using a quasi-experimental design (Haslam & McGarty, 1998) with a number of experimental and control conditions as will be set out in Chapter 10. The shift to a focus on individual and group differences (Collins, 1999), coupled with the scientific and statistical rigour of a positivist methodology (Dawes & Donald, 1994) was considered to be necessary as the basis for making informed decisions about the relative effective of different intervention strategies. In turn, this would provide the empirical evidence on which a judgement could be made in terms of the possible up-scaling of the programme (Germann & Mädörin, 2002).

7.5. The process of community selection:

The selection of community sites was based on non-probability purposive sampling. The strength and logic of this sampling method enabled the researcher to gather an "information rich" (Patton, 1990, p.169) sample to evaluate the effectiveness of the programme. The selection criteria were:

(1) *Geographic region*: On the basis of their geographic setting, eleven communities were identified as potential sites for the intervention programmes. There were two informal settlements and three each of urban townships, peri-urban and rural communities. Problems were encountered with the informal settlements (See Section 7.5.1) and they were subsequently dropped from this study. Communities categorised themselves according to type of region, however more rigorous specifications were explored in the community profiles.

(2) *Increase in recent mortality rates*: The researcher wished to work in communities that had high HIV/AIDS prevalence, defined for the purpose of this study as an increase in deaths, especially of young people. The degree of stigma associated with HIV/AIDS precluded accessing communities by introducing the topic of HIV/AIDS until such time as a trusting relationship had been developed. It had been discovered, during early community contact, that introducing the topic of HIV/AIDS created resistance. Therefore, a conservative approach was adopted in which HIV/AIDS discussion was deferred until sufficient trust had been established between the researcher and community members. Carefully considered strategies were required to see if the criteria for communities had high HIV/AIDS prevalence rates.

Identifying communities likely to meet the first criterion involved systematic consideration and networking within NPO and CBO groups. The researcher enjoyed pre-established, long-term relationships with certain community members in most of the partnering communities. Productive discussion and debate about vulnerable children took place while these relationships were rekindled and entry into the communities was secured. Each community that was approached was found to be suitable for inclusion.

The recent increase in mortality as a criterion for selecting partnering communities required an initial data gathering procedure. Once potential communities were identified on the basis of the first criterion, an informal survey was conducted using two respondent sub-groups to assess mortality rates within a community: (i) Five key stakeholders in each community were identified using snowball sampling (Patton, 1990) on the basis of their presumed special insight into community

demographics (Robson, 2002). This group of respondents included the *Amakhozi* and *Indunas* (the traditional leadership), the political leaders (representing local, provincial and national government structures), the leaders of FBO's (the church ministers, the Pentecostal leaders and Zionist pastors) as well as chairpersons or executive members of community development forums. (ii) A convenience sample of twenty people from each of the potential communities was identified. People who were attending meetings, waiting for public transport, or sitting at clinics were approached and asked if they would be willing to respond to a few questions. The only criterion for inclusion in this survey was that they were resident in the community. There was a large degree of homogeneity within each partnering communities, so this initial informal survey was simply a preliminary data gathering exercise. Nevertheless, care was taken to include people of both genders and from different age groups.

The survey consisted of the following five questions. The exact wording differed according to the respondent and the need to establish rapport.

1. ***Increased number of deaths:*** *Do you feel that there are more people dying in your community now than ever before? Are there more deaths now than this time last year?* An affirmative response from 89% of the respondents (87.2% of informal respondents and 88.88% of key stakeholders) was obtained across the nine partnering communities (this excludes the informal settlements).
2. ***Attendance at funerals over the immediately preceding two months.*** *How many funerals, for people from this community, have you personally attended over the last two months?* The respondents were encouraged to give the first name of the deceased and were then asked to approximate his or her age at the time of death. Although there is no suggestion that all of these deaths were AIDS-related, it is reasonable to presume that a proportion, especially of the younger people who had died, could be attributed to AIDS-related conditions. It was interesting to note that criminal violence, motor vehicle accidents and suicide were also considered to be major causes of death. Across the nine communities, respondents reported having attended an average of 19 funerals over the preceding two months, with a mean of 16.8 from the three township areas, 18.5 from the three peri-urban areas and 22 from the three rural areas. The average age at death was 25.3 years: the estimated average age for township regions was 26.2 years, 23.5 years in peri-urban areas and 26.1 years in the rural areas (see Table 7.3). The relatively young age of the deceased was consistent with the pattern associated with AIDS-related deaths (Shisana & Simbayi, 2002). This connection was not made explicit by the researcher, but some respondents (15%) spontaneously raised the matter

themselves, usually with reference to the stigma associated with HIV/AIDS. The responses obtained from people in the informal settlements were not regarded as reliable community statistics as they varied greatly between respondents and appeared to reflect deaths from communities other than their own.

3. **Orphanhood:** *Do you know children in this community who are orphans, or who are likely to become orphans in the near future? Can you name them and give their approximate ages?* The naming process was included to obtain an estimate of the breadth of the problem. It was possible that there were a few well-known orphans with whom many people were familiar. No validity checks on the lists were made. Certain children were repeatedly mentioned by respondents. The question of why some children have high social visibility, whilst others were identified only during door-to-door surveys was an issue that needed to be considered by both the researcher and the community during later stages of the intervention. An average of 48 orphans were identified from the three township regions, with the average across the three peri-urban and three rural areas being 52 and 65.6 respectively (see Table 7.3). Across all nine partnering communities, the average number of identified orphans was 55.2. It would appear, from this informal survey, that the rural communities are bearing the brunt of orphan care.
4. **Willingness to commit to action:** *Do you think that there are people in your community who would be willing to work together to help children who are experiencing especially 'difficult lives'? Can you name them? Are you willing to be involved?* Responses to this question generated lists of people to be invited to community mobilisation meetings and potential participants in the SP.
5. **Difficulties experienced by children in the community:** *What do you think are the major difficulties experienced by children in this community?* The responses to this questions were not used for selection purposes. They merely provided the researcher with some indication of the communities' perceptions of the problems facing children. The three most frequently identified difficulties were poverty-related circumstances (including responses of 'no money', 'no food', 'parents are unemployed', 'no school fees', 'no health care'), orphans, and child abuse and neglect (Table 7.3). The communities seemed to distinguish between sexual abuse, which was frequently linked to rape and other forms of child abuse such as physical beatings and neglect. The category of parental alcoholism covered drunkenness and substance abuse. Alcoholic beverages and traditional beers were frequently mentioned as the substances most likely to be abused.

Table 7.3. Community selection:

Community	A	B	C	D	E	F	G	H	I	MEAN	J	K
Region	Township	Township	Township	Peri-urban	Peri-urban	Peri-urban	Rural	Rural	Rural	NA	Informal settlement	Informal settlement
NPO/CBO	NPO	CBO	CBO	CBO	CBO	NPO	NPO	NPO	CBO	NA	CBO	NPO
% confirming rapid increase in deaths	KS: 90% CM: 95%	KS: 80% CM: 75%	KS: 85% CM: 75%	KS: 90% CM: 90%	KS: 80% CM: 85%	KS: 90% CM: 90%	KS: 100% CM: 100%	KS: 90% CM: 85%	KS: 95% CM: 90%	KS: 88% CM: 87,2%	KS: 90% CM: 85%	KS: 90% CM: 80%
N. funerals in last 2 mths.	KS = 17 CM = 14	KS = 18 CM = 16	KS = 19 CM = 17	KS = 19 CM = 14	KS = 22 CM = 22	KS = 18 CM = 16	KS = 21 CM = 19	KS = 23 CM = 24	KS = 22 CM = 23	KS = 19,8 CM = 18,3	KS = 10 CM = 22	KS = 13 CM = 28
Mean age of deceased	26,3	27,7	25,3	25,6	24,3	20,7	25,8	28,0	24,6	25,3	Not reliable	Not reliable
N. orphans identified by name	53	45	46	54	48	54	58	65	74	55.2	Not reliable	Not reliable
Problems experienced by children	Poverty Abuse Alcoholism	Poverty Rape Physical abuse	Orphans Sexual abuse Neglect	Poverty Orphans Sexual abuse	Orphans Alcoholism Sexual abuse	Poverty Orphans Sexual abuse	Poverty Orphans Neglect	Orphans Poverty Alcoholism	Poverty Alcoholism Orphans		Poverty No water No electricity	Poverty Unemployment Neglect

Key: KS = Key stakeholders, CM = Community members.

* See Section 3 for more details about how these decisions were reached in this regard. Experimental Group 3 was not drawn from any of the above mentioned communities Selection criteria for this group are presented in Section 3 of this dissertation.

The purpose of this informal survey was to ensure that those communities selected for inclusion had experienced a recent increase in mortality rates, had orphans and other vulnerable children, and that there were likely to be people willing to volunteer time and energy. There was high intra-community consistency for those people who resided in townships, peri-urban and rural areas, with very little variance between and within the responses from key stakeholders (KS) and community members (CM) (See Table 7.3). All of these communities had experienced recent increases in the number of deaths, especially of young adults and children, were able to identify a significant number of orphans and vulnerable children, and indicated a willingness to help vulnerable children.

This informal survey indicated that the people in impoverished rural areas had more funerals and were carrying greater responsibility for orphans and other vulnerable children. This appeared to contradict the HSRC survey (Shisana & Simbayi, 2002) where the highest rates of HIV infection were found to occur amongst informal settlement dwellers. This apparent contradiction is seen to reflect the fact that they had used different sampling procedures and had a different focal area. The community members in this research reported that after becoming too ill to work, people would generally retreat to their rural homes to be cared for and to subsequently die. In addition, rural environments were considered by community members (especially township dwellers) to be better places in which to raise children. Despite the high incidence of HIV infection in informal settlements (Shisana & Simbayi, 2002), difficulties were encountered in applying the current model of intervention within the informal settlements.

7.5.1. Difficulties with the informal settlements:

As with all of the partnering communities, CMM's were held in two informal settlements to discuss the needs of children. However, during these meetings very little time was dedicated to discussing children. It became evident during these CMM's that the residents experience so many hardships that their socio-political agendas could not prioritise vulnerable children. For example, in three of the CMM's, each lasting in excess of two hours, less than fifteen minutes of the discussion was devoted to the needs of children, despite the fact that the meeting had been advertised as a forum in which community members could discuss children. The informal settlement residents clearly had far more pressing needs to lobby for services, establish democratically elected leadership structures, and to find strategies to deal with their many and varied crises. The lack of mobilisation around vulnerable children, and the inability of the communities to identify potential volunteers to offer PSS to children, meant that the strategy that would be appropriate for these areas would differ substantially from the other communities.

In addition, the responses from the informal settlement residents were highly inconsistent. They recognised the recent increase in deaths and funerals but found it difficult to provide names or other details of the deceased to a relative stranger. When pressed for details, they either retracted their earlier statements of increased mortality rates (45% said they did not personally know anyone who had died) or generalised by asserting that there were so many funerals that it was difficult to specify names and details. Only 32% of respondents in the two informal communities could name people who had died or were orphaned. They explained that most people live in informal settlements to secure employment but their 'real homes' were elsewhere, in rural or peri-urban areas. Therefore, when people became very ill they returned home and away from the struggles associated with living in informal settlements. Although there were many children in the informal settlements, most respondents stated that orphaned children would not live there but would rather be sent to live with extended family in rural areas.

The lack of success in the informal settlements could be explained by various factors. For example, the researcher's inability to establish credibility and partnerships within these communities, or the pressing need for them to prioritise basic protection and survival issues. These difficulties have implications for the way in which this form of intervention could be used in informal settlements. As a result, the informal settlements were dropped from the current research programme since they did not 'buy-into' the community mobilisation process - a process that is considered to be a pre-requisite for this form of intervention.

7.6. Issues of translation and concept interpretation:

The Chinese scripting for the word 'crisis' comprises two characters: one that reflects 'danger' and the other 'opportunity'. The crisis of working within cross-cultural settings, necessitated special attention to the interpretation of concepts and translation, as well as to the suitability of the psychometric measures that were to be used in the evaluation of the SGTP. This created an opportunity for real collaboration and knowledge development between community members and the researcher.

Enormous difficulties were experienced in accurately translating and interpreting ideas and concepts. These difficulties were magnified as the researcher had to rely on the input of others in order to ascertain the accuracy of translations and interpretations during all phases of the intervention and especially during the conduction of the SP and the SGTP. It is believed that working within a PAR ethic enabled these difficulties to be circumvented with relative success.

Most of the participants were mother tongue *isiZulu* speakers. Many also had some English fluency, and it soon became clear that when one person offered an English translation of an *isiZulu* contribution (or vice versa), debate and discussion about the accuracy of the translation frequently occurred. Often, the translator also needed to discuss how to translate/interpret from one language to the other. It seemed that there were a number of sources of error that had to be taken into consideration: (i) *isiZulu* is a language rich in its use of metaphors (Mbiti, 1989) and the basic grammatical structure differs considerably from English. This created space for interpretation by individual respondents - a process that may have threatened the internal validity of the entire process (Tredoux, 2002). (ii) Many English words, particularly those that have conceptual meanings, were not part of ordinary *isiZulu*. This lack of terminology made the process difficult. (iii) It soon became apparent that there were geographically-based dialectic strands of *isiZulu* that had developed within specific regions, making it difficult for people in one community to understand the phrases used in a different community. (iv) The degree of exposure to westernisation, education and media differed substantially across communities. In fact, people with tertiary education proved to be the least useful in offering translations since the 'dialect' that they spoke was frequently incomprehensible to community members.

In addition, the researcher wished to use psychometric tests to summatively evaluate the effectiveness of the SGTP by measuring manifest symptomatology (including depression, conduct difficulties, traumagenic and other childhood problems), self esteem and social support. South African psychological literature is relatively devoid of valid and reliable instruments suitable for *isiZulu* subjects (Swartz, 1998). Therefore, there was little choice but to rely on tests that had been derived from western contexts. It was hoped that the sample size would generate a database that could be used to establish the psychometric properties associated with the selected tests, even though the tests were to be used with children who had experienced extreme conditions of adversity and risk.

The translation and interpretation of terms and concepts, especially for semi-literate or illiterate subjects who spoke *isiZulu*, presented an enormous challenge. The basic translation and interpretation procedure began by selecting and/or developing questionnaires on the basis of their applicability to the dependent variables being investigated (See Chapter 10). Adhering to the procedure suggested by Brislin (1986, in Swartz, 1998), the selected instruments were translated from their source language (English) into the target language (*isiZulu*). An independent mother-tongue *isiZulu* speaker (who is fluent in English) then translated from the target language back to the source language. The original English version and the back-translated version were then compared. There were so many discrepancies that the entire process

had to be reviewed. For research (and intervention) purposes, it is essential that one knows precisely what respondents understand about what is being asked of them. "This involves more than accurate translation and back-translation - it requires us to find out, as far as we are able, whether the meaning we give to any instrument has the same meaning for our respondents" (Swartz, 1998, p. 210). The discrepancies that arose during the back-translation procedures showed that at best this could be regarded as a mere first step in translation since there was a lack of clarity about the nature of the constructs being measured in the tests. A different procedure had to be found to deal with these difficulties.

In order to address these problems, community members who were relatively fluent in both languages, and confident enough to challenge the researcher about meanings, were engaged (on a voluntary basis) as research assistants/co-facilitators. Research assistants were recruited from each of the partnering communities. During 3-day workshops, they were trained in interview techniques, data collection, questionnaire administration and research rigour and ethics. Working within small groups, the research assistants were encouraged to translate and interpret the concepts and ideas - a process that some individuals reported to be especially affirming of their home language and their ideas. Numerous translations and back-translations were produced and much sharing of information took place. These discussions, usually with young people, but inclusive of local *Amakhosi* and other community leaders in five instances, proved to be extremely useful. The debates and discussions proved to be extremely useful as people became actively engaged with concepts while trying to find the best translations. In effect, this meant that the translation process served an educative function for both the researcher and the research assistants. It enabled the questionnaires to be understood and a shared meaning to be developed. At the suggestion of the research assistants, the printed questionnaires included the English version as a memory cue that would enable them to question around an issue to ensure that the respondent had grasped the meaning of a question.

During these research assistant training workshops, it became apparent that community members were frequently linking certain behavioural criteria to psychosocial vulnerability. It was possible that these criteria could form the basis of a culturally-defined specification of psychosocial risk and vulnerability. Therefore they were incorporated into the questionnaires for the purpose of measuring their frequency and co-existence with more western-based diagnostic criteria. The possible relationship between these criteria and exposure to the risk factors will be explored later in this chapter.

The translation process was extremely time consuming but ultimately it proved to be useful in developing

synergistic co-operation between the researcher and community members. There was much discussion and challenging of the meaning of questions and concepts. At times, there was no clear resolution of these difficulties with the debates acknowledging diversity and ambiguity. Nevertheless, it is believed that this protracted translation process was beneficial in that it (i) evoked much interest among community members; (ii) demonstrated the researcher's genuine search for shared meaning; (iii) was empowering and capacity building for the participants who became the research assistants for the data collection; (iv) served to deepen and equalise relationships between research assistants and the researcher; (v) led to the development of social groups within each community who felt integrally involved, frequently became the driving force behind community-based initiatives, and enrolled as apprentice-facilitators for the SGTP or one of the control conditions; and (vi) was great fun! Most importantly, this process of translation and training of community-based research assistants, powerfully demonstrated a commitment to bi-directional knowledge sharing and understanding between the community members and the researcher.

7.7. Ethical considerations:

Strict adherence to research ethics was required in designing, implementing and evaluating this programme. The research context was primarily within disempowered, impoverished and stigmatised communities in which there was potential for a perception of an implicit power differential between the community members and the researcher. The researcher, with her educational background, from the university, would drive into communities bearing food, drink and training materials. This potentially placed the community members at a serious disadvantage. There was a need to constantly and sensitively create opportunities for genuine participation and power-sharing. It was also critical for research assistants to be trained in ethics. In-depth discussions using case vignettes to demonstrate the major ethical dilemmas and principles, as well as the possible consequences of ethical transgressions were used in this training. A number of ethical principles required careful consideration both in the design of this research and in training research assistants.

7.7.1. Child Subjects: The seminal study on working ethically with child subjects was published by Boyden and Ennew in 1997 (Clacherty & Associates, 2001). They list a number of considerations that relate specifically to children: (i) Respect and support the United Nations Convention on the Rights of the Child (UNICEF, 1989). (ii) Promote children's physical, psychological and social development. (iii) Wherever appropriate, obtain informed consent from children and their parents. (iv) Honour children's priorities, interests and cultural values. (v) Treat children as adequate and capable social actors; (vi) Do

not discriminate against children on the basis of age, gender, socio-economic status, caste, religion, language, race, ethnicity and capacity. In the current context, the researcher was careful not to use health status as a criterion for selection of subjects. (vii) Involve others who are committed to working with and for children in child-centered participatory research processes. (viii) Emphasise the ethical and conceptual aspects of the learning process while involved in capacity building. (ix) Work to raise awareness of individuals and organisations about child-centred participatory approaches. It is believed that every endeavour was made to adhere to these guidelines and to raise sensitivity to children's needs and rights within the partnering communities.

7.7.2. Autonomous informed consent: The principle of autonomy is basic to all ethical codes (Durrheim & Wassenaar, 2002; APA, 1992, in McBurney, 2001). The process of obtaining informed consent required the researcher to have an awareness of the political climate and an understanding of power dynamics between stakeholders within the communities (Kelly, 2002). With respect to traditional *isiZulu* culture, the *Amakhozi* were regarded as major stakeholders in those communities that fall under tribal authority (the peri-urban and rural areas). However, deferring to the authority of the *Amakhozi* could have created an impression that the researcher was aligned to a particular tradition (ibid.) that may not have been accepted by all stakeholders. To pro-actively preempt this potential difficulty, it was decided to use multiple entry points in each community. This had the advantage of establishing networks and mobilising key stakeholders. Every effort was made during all community meetings to ensure that individuals did not feel the need to comply either with the wishes of those who may have been perceived to be more powerful or knowledgeable, nor to conform to majority wishes.

Informed consent was achieved by conducting PowerPoint Presentations in *isiZulu* and English. These presentations gave an overview of the entire intervention and research programme. Several CMM's were conducted in each of the selected communities, usually with different individuals or community groupings attending each of the meetings (see Appendix B). Participation was strongly encouraged. The objective was to promote discussion about vulnerable children, to outline the nature and purpose of the programme, and to introduce potential roles for volunteers who were willing to commit time and energy to offering PSS. The researcher's expectations of the volunteers were made explicit, with special caution about raising false expectations about personal or community gain. This was especially important in areas where the unemployment rates were extreme.

After the CMM's, participation in the research programme was discussed in individual interviews

between participants and the researcher or the research assistants. If it seemed that the adult or child understood the implications of participation and their rights to withdraw at any time, they were asked to complete an informed consent form, as appropriate for child, parent/primary-caregiver, community member, or apprentice facilitator (See Appendix D). The process of obtaining informed consent in a manner that ensured adherence to the ethical principle of autonomy was time-consuming, and at times frustrating, as it appeared to delay the implementation of the programme. Nevertheless, it was recognised that this process of negotiation was a key investment. The success of the programme was dependent on the informed autonomous consent of each role-player.

7.7.3. Confidentiality: The fact that the research was conducted within community settings raised issues pertaining to the ethical obligation to ensure confidentiality for participants (Durrheim & Wassenaar, 2002). The focus on vulnerable children (defined as children who were experiencing 'especially difficult lives') served to shift the focus from potentially more stigmatising labels. Efforts were made to conceptualise the difficulties as being external to the child with a simultaneous focus on formulating strengths-based models of resilience (Howard & Dryden, 1999). The programme demanded a strong formal focus on the adherence to ethical behaviours. 'Pledges of Confidentiality' were explained and signed by all research participants, with regular re-visiting of the concept of confidentiality during all stages of the programme. Community gossip was an issue that troubled many of the participants and needed specific attention, by openly discussing the need for strict adherence to confidentiality and training the research assistants using various case vignettes.

7.7.4. Competence: Beneficence: The ethical responsibility of competence (APA, 1992; McBurney, 2001) requires psychologists (and by inference community workers) to only undertake tasks for which they have been adequately trained and supervised. All work was clinically supervised by the researcher, a clinical psychologist with many years of experience in both community and child psychology. On the occasion when an external consult was required, supervision with a colleague was sought - this is consistent with usual clinical practice. The SGTP was conducted by at least one qualified and registered psychologist at each community site. The researcher and the qualified psychologists held the ethical and professional responsibility for the well-being of the adult and child subjects. The use of an apprenticeship model of training offered extensive supervision and enabled apprentice-facilitators to grow in competence, gain insight into their own areas of strength, and to confidently acknowledge their own limitations.

7.7.5. Competence: Nonmaleficence: The principle of nonmaleficence implies sensitivity to both acts of omission and commission. The axiom of 'least harm' (Boyden & Ennew, 1997, p. 43) requires that participants are not exposed to additional risk and that the advantages of participation outweigh the benefits of non-participation (Clacherty & Associates, 2001). Therapeutic processes can stir up emotions that individuals may prefer to keep suppressed rather than expressed (Moustakas, 1955; Esman, 1983). It was difficult to explain to community members that children may become angry or tearful, and that this was considered to be good for them. In practice, this required community members to take a leap of faith and trust in the skills of the researcher. This was an onerous responsibility, requiring a process of debriefing for community members on completion of each of the SGTP sessions (Durrheim & Wassenaar, 2002). Individuals who had participated in the SP had already been exposed to the benefits of expressing their own feelings, instead of the more culturally endorsed practice of "keeping things bottled up."

Working with vulnerable subjects (child or adult members of disempowered communities) in communities that the researcher had labelled as being high HIV/AIDS prevalent raised sensitive issues. Many of the communities would have been stigmatised and discriminated against by virtue of their race, ethnic and socio-economic status. Involvement in the programme could have led to negative overt or covert repercussions for the participants. Following the guidelines of the major role players in the HIV/AIDS field, the focus was primarily on vulnerable children, as opposed to orphans (Germann, 2002; Hunter & Williamson, 2002; UNICEF, 2001). Many of the participants were initially unable to discuss HIV/AIDS prevalence in their communities, preferring to rather see the deaths as related to bewitchment or other circumstances. Care was taken not to challenge this denial or belief system. As trust developed, most participants were more able to spontaneously acknowledge that the increase in deaths could be AIDS-related. At this stage, open discussions about the HIV/AIDS pandemic took place.

7.7.6. Reporting procedures: Care was taken to protect the identity of all subjects (communities and individuals) by using a category or numerical system in this and any subsequent publication of research programme.

More detailed descriptions of the methodologies used for each unit of analysis (community and children) are presented in the subsequent two sections. Section 3 will focus on the community unit of analysis. Section 4 will report the methodology, results and discussion relevant to the summative evaluation of the SGTP.

7.8. Describing the context:

In this section the context in which the programme was implemented and evaluated is described for the purposes of (i) providing the reader with some insight into the life circumstances of the subjects in this study; and (ii) enabling mental health and community workers to ascertain the programme's relevance to other situations. The descriptive statistics on the communities and the circumstances of children living in these communities are presented. The data are derived from two sources: (1) the Community Profile Questionnaires (See Appendix G), administered to SP participants, described the partnering communities in terms of general demographic, socio-economic and other community-based factors; and (2) the questions contained in the Parent/Primary Caregiver Questionnaire (Appendix K) that relate to children's exposure to adversity and experience of death. The data obtained from this part of the Parent/Primary Caregiver Questionnaire was used in three ways: (i) as an indication of the circumstances of children living in the partnering communities in terms of their exposure to risk; (ii) to discern differences between orphaned children, children rendered vulnerable due to circumstances other than orphanhood, and non-vulnerable children living in the same communities; and (iii) as a covariate in the multivariate analysis for the summative evaluation of the SGTP. (see Section 5).

7.8.1. Community profiles:

Much of the effectiveness of this intervention programme could have depended on specific community and individual variables. During the initial forays into the communities, it became clear that children enjoy different degrees of care and concern within different communities. For example, children were not afforded priority status in the informal settlements at the time of this researcher conducted her CMM's. The data collected during the community selection process described above, lacked some of the rigour and depth of information that could be potentially be gained about the communities in which the research was to be conducted. The purpose of the community profiles was to investigate more thoroughly community demographics, household compositions, religious orientation, socio-economic status and community cohesion.

There are a number of community variables that could potentially be significant in terms of the effectiveness of the intervention. These include traditional cultural beliefs and practices, sense of belonging and cohesion within a community, the presence of social support structures, commitment of key community members, the presence of positive role models, etc. From the perspective of the individual, age, gender, personal experience with HIV/AIDS-affected individuals, religious orientation, or hardship during childhood are among the variables that potentially could impact on the programme's

effectiveness and the willingness of individuals to become volunteers offering PSS to children. These were investigated by Gothan (2003) who interviewed the SP participants to explore the factors that motivate people to volunteer in the current research contexts. Her work falls outside of the focus of the current study but contributes to our understanding of the process of volunteering. In the current study, the usual demographic variables, and measures of community cohesion and religious orientation were collected. It was also opportune to describe household composition, living conditions, socioeconomic factors and personal exposure to the HIV/AIDS pandemic. The Community Profile Questionnaire (CPQ) was developed to measure these variables (See Appendix G). The questions were designed to include information pertaining to the individual respondent as well as requesting the respondent to reflect on how his or her own position compared to other members of his/her community. The variables considered in the CPQ are:

1. **Basic biographical data** included age, gender, educational and marital status, religious affiliation, personal experience of death and AIDS-related illness and the length of time that the respondent had been resident in the community.
2. **Household demographics** in terms of (i) number of people in various age ranges resident in the respondent's home; (ii) socioeconomic variables included the amount and source of income as well as access to social grants; and (iii) housing conditions with respect to the structure and facilities in the respondents' homes. Respondents were requested to indicate their personal circumstances and compare themselves with others in their community.
3. **An opinion survey** on the nature of problems affecting children in their communities. The questions used to select partnering communities were repeated as a cross-check on the earlier more informal surveying (See 7.5) of the nature of problems that beset children and prevalence of HIV/AIDS (indicated on the basis of recent upsurge in mortality rates).
4. **Religious commitment and practice** in terms of the meaning that prayer and other religious practices have in the respondents' lives. Spiritual beliefs have been documented as important motivators for people to help others (Mallman, 2002). The commandment to help others, especially those in great need, is integral to all religious teachings. It was interesting to note that at all of the community meetings, the chairperson (always a community member) began the meeting by requesting that someone volunteer to lead prayers and perhaps a hymn as well. In most of the meetings, closure was similarly marked with prayer and/or hymns.
5. **The Neighborhood Cohesion Instrument (NCI)** (Buckner, 1988) ascertains the degree of community cohesion and satisfaction to be part of a particular community. Much has been written about the collectivist ideology that forms the foundation of Afrocentric cultures (Kelly, 2002; Mkhize, 2004;

Swartz, 1998). In addition to disregarding basic human rights, the apartheid regime was a system of social engineering that worked to destroy indigenous, social and domestic structures (Editorial, *Natal Witness*, 13 Sept 2002, p. 12). The process of fragmenting communities was an integral aspect of the *apartheid* regime and the faction fighting that it created (Lachman et al., 2002; Higson-Smith & Killian, 2000). Consequently, it was plausible that the collectivist nature of African societies had been severely eroded in terms of day-to-day applicability in people's lives. It was thus necessary to measure 'sense of community' as this had the potential to differentiate between communities in which the programme was effective and those in which there was a lack of success.

The 18-question NCI was administered as part of the CPQ. Respondents indicated agreement or disagreement to the various statements. It had been designed to measure a synthesis of three inter-related concepts: (i) psychological sense of community; (ii) attraction-to-neighbourhood; and (iii) social interaction (Buckner, 1988). It has been used effectively to evaluate community intervention strategies (*ibid.*), and can yield the collective attribute of community cohesion as well as individual sense of belonging to a community. The collective-level of analysis is obtained by considering inter-subject consistency and by utilising aggregated responses to characterise the cohesiveness within a specific community (*ibid.*).

Neighbourhood is a concept that was deemed to be unfamiliar to the participants in the current study. Thus, the word 'neighbourhood' was replaced with 'community'. In the original standardisation of this questionnaire, 206 residents in three diverse neighbourhoods showed that the questionnaire had good internal consistency ($\alpha = 0.95$), adequate test-retest reliability (ranging from $\alpha = 0.64$ to $\alpha = 0.92$), discriminatory power and criterion-related validity in the assessment of neighbourhood cohesion (*ibid.*). The three subscales were subsumed under one cognate factor of neighbourhood cohesion on the basis of high loadings of all three subscales on a single rotated factor, labelled "sense of community/cohesion" (Buckner, 1988, p. 779).

Translation of the CPQ took place according to the procedures outlined in Section 7.6 above. The CPQ was administered to approximately 20 community members from each of the nine partnering communities. Purposeful random sampling, combining systematic and randomised selection of respondents was used (Patton, 1990). Participants were asked to volunteer to complete the CPQ and if it seemed that there was too much homogeneity amongst those who volunteered, participants from other groups were asked if they would be willing to complete the questionnaire. The people who completed

the CPQ were not necessarily representative of the community as a whole. The homogeneity within most partnering communities was apparent and the high percentage of respondents from each SP seemed to adequately serve the purpose of describing the circumstances of the SP participants and their communities.

The *isiZulu*-speaking research assistant asked individuals if they were willing to complete the questionnaires. The ethics and their rights in this regard were explained to them. If the person appeared keen and motivated, the research assistant helped them to complete the questionnaire (low literacy rates required assistance for many of the participants to complete forms). Special attention was given to establishing the boundaries of confidentiality between the respondent, the research assistant and the researcher. The data was then coded and entered into a database for analysis. The name of the respondent and their contact details were not captured. The completed questionnaires are kept in locked files. The data was analysed primarily for descriptive statistics.

7.8.2. Description of the Community Context:

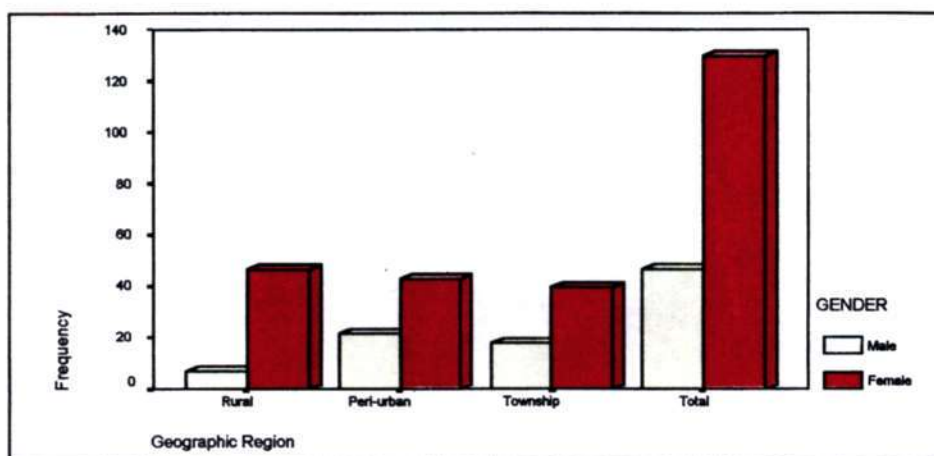
254 people participated in the SP that was conducted in the nine communities. On average 28 people participated each time that the SP was conducted. Three communities from each of the different geographic regions (rural, peri-urban and township) were selected (see 7.5). The differentiation between the geographic regions was consistent with the communities' own categorisation of the regions and were very obvious when one visited particular areas. Various difficulties were encountered in the informal settlements resulting in these communities being dropped from the study (see 7.5.2.).

177 (69.69% of the total) of the SP participants (a quota sample of approximately 20 people from each community) completed the Community Profile Questionnaire (CPQ)¹. 73,4% of the respondents were females and 26,6% were males (See Figure 7.1). The spread across geographical regions indicates that 31% (n= 54) of the respondents were from rural areas, 37% (n = 65) were from peri-urban areas and 33% (n = 58) from townships (See Figure 7.2). There were gender and age differences across the geographic regions, with very few men from rural areas participating. In two of the rural areas, there were no male participants at all. This was an interesting feature in that the *Amakhosi* in their two areas had decided that the community would hold elections to decide who would be the community representatives to take responsibility for the vulnerable children . Although men who expressed an interest

¹ Most of the data in this chapter will be presented in terms of percentages in order to facilitate comparison across the different variables.

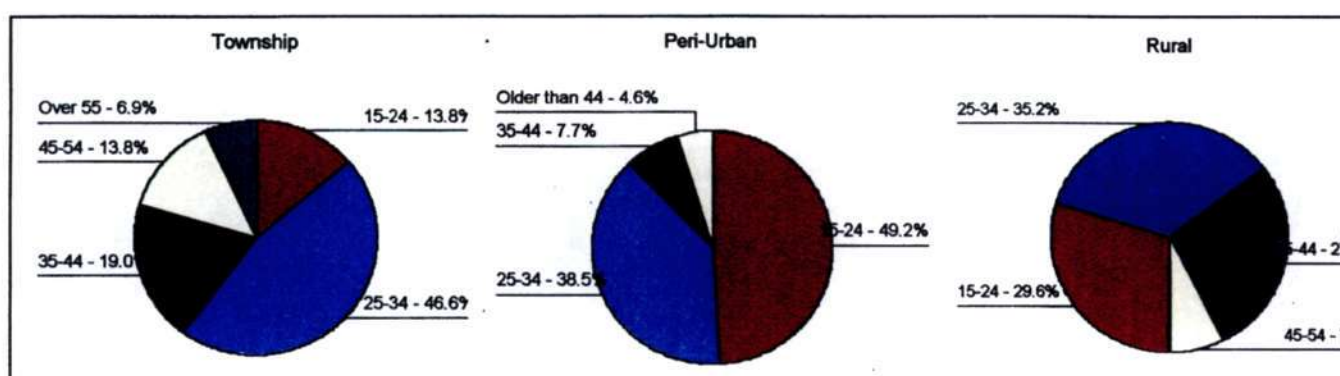
in serving their community by offering PSS to vulnerable children, the voting perhaps demonstrated a community attitude that women are better suited to the task of caring for children.

Figure 7.1: Percentage of CPQ respondents by gender and geographic region:



The mean age of the CPQ respondents was 31.2 years, with a standard deviation of 13,27, and an age range of 15 to 72 years. Young people were especially prevalent in the peri-urban groups, probably since youth groups affiliated with a local NGO were selected as an access point in some communities. The rural groups did not include people in the older age groups. Note that the pie charts in Figure 7.2 indicate the percentage of people in each age group from the different regions.

Figure 7.2: Age distribution by geographic regions (% frequencies).



In terms of religious affiliation, 42% were Christians, 20% Zionists, 17,6% Catholic and 20,5% denoted the 'other' category. The rank ordering of responses in the 'other' category indicates "Born-Again" Christians, Shembe, Traditional and None. There were geographic differences in terms of religious affiliation, with Zionism being more prevalent in the rural areas (Table 7.4). The questionnaire was incorrectly designed in categorising Christian and Catholic as two

separate possible responses since Catholics are Christians. However, it is believed that those who attend the Roman Catholic Church responded as Catholics. Many of the respondents indicated that they were Christian and then wrote in Methodist or Anglican.

The majority of the respondents (78%) indicated that they pray on a daily basis, while 1,7% indicated that prayer was not important in their daily lives and no one admitted to never praying (See Table 7.5). The commitment to a deep spiritual life was further demonstrated when all meetings began and ended with prayers and hymns. An individual would spontaneously volunteer to lead the prayers and then thank God for all of His Blessings and ask for assistance in carrying out God's Will to develop their communities and help the children. These heartfelt prayers were extremely relevant to the material covered in meetings. The hymn singing was spiritually moving and extremely beautiful.

Table 7.4: CPQ respondents' religious affiliation by geographic regions:

Religion	Rural	Peri-urban	Township	Total
Christian	31,5%	33,8%	60,3	41,8%
Zionist	25,9%	24,6%	8,6	19,8%
Catholic	24,1%	15,4%	13,8%	17,5%
Other	18,5%	24,6%	17,2%	20,5%

Table 7.5: CPS respondents' prayer life by geographic region:

	Peri-urban	Rural	Township	Total
Prayer is part of daily life	43 (63%)	47 (76%)	48 (69%)	138 (69%)
Pray at formal ceremonies	0 (0%)	2 (3%)	2 (3%)	4 (2%)
Pray in times of need	23 (34%)	11 (18%)	17 (24%)	51 (25.5%)
Never Pray	2 (3%)	1 (1.5%)	1 (1%)	4 (2%)
Prayer has little importance	0 (0%)	1 (1.5%)	2 (3%)	3 (1.5%)

Most (77,3%) of the respondents described themselves as single¹, 15,9% were married and 4,5% were widowed. No one was divorced. The respondents had an average of 1,68 children, with a standard deviation of 1,8. Many respondents had no children and some had up to ten children

¹ The local cultural tradition requires the payment of bride price – *lobola*, -many couples regard themselves as single until the full *lobola* has been paid, even though they may be living together and have children.

(See Figure 7.3). The older individuals were more likely to have several children, while many of the younger respondents had no children.

The mean number of people living in each household was 8,66, with a standard deviation of 4.1 and a range of 2 to 24 people in one household. This suggests that most of the respondents live with extended family. Furthermore, the larger household compositions were found among the rural respondents (see Figure 7.4).

Figure 7.3: Number of children per respondent:

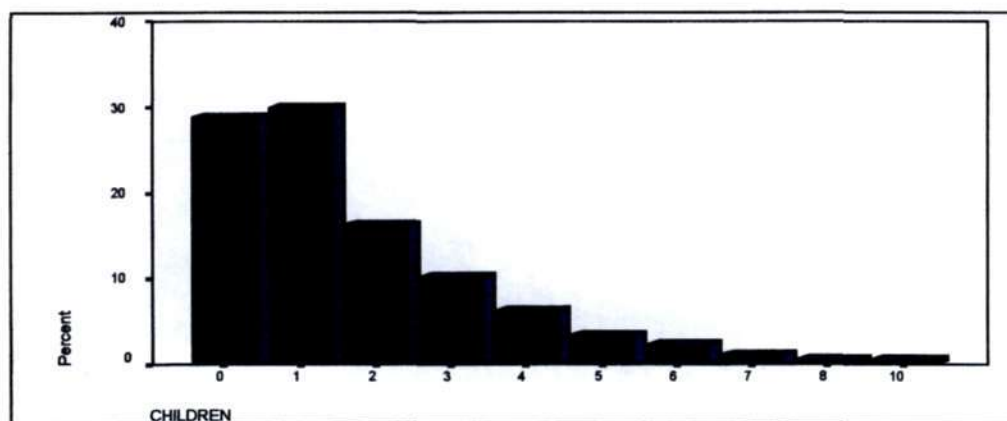
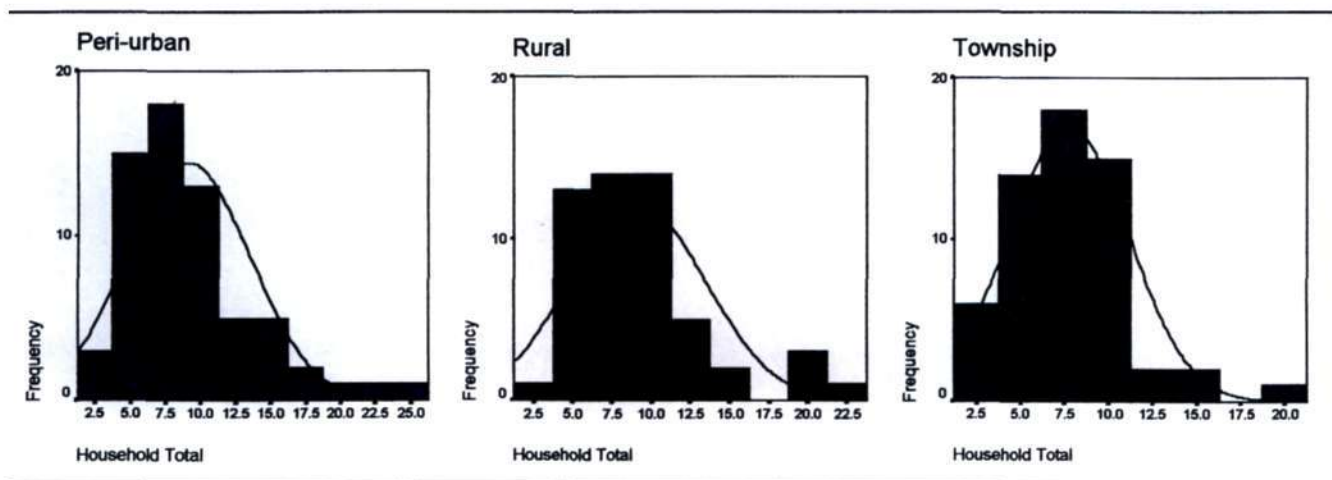


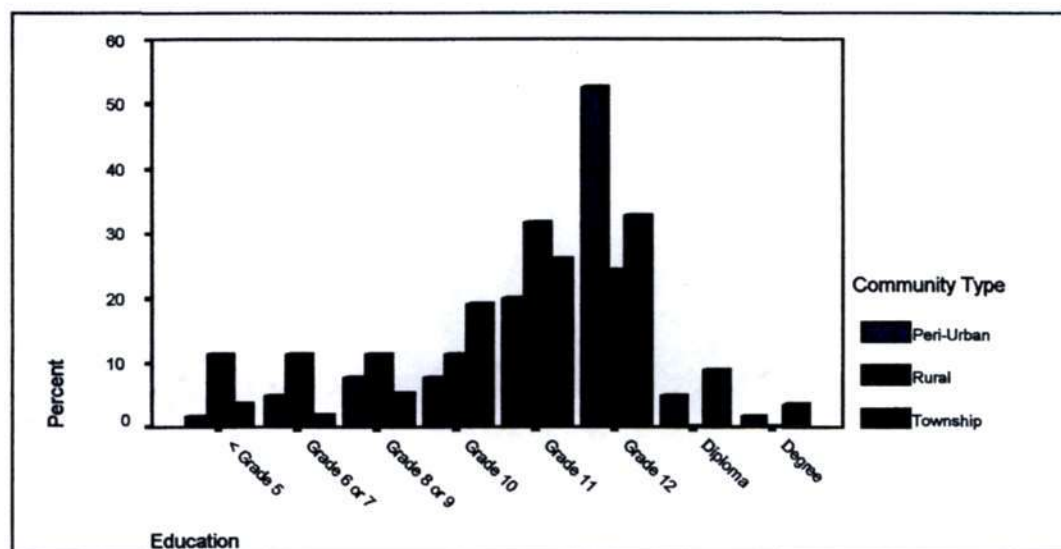
Figure 7.4: Number of people per household by geographic regions:



Across all of the communities, 38% of CPQ respondents had attained Grade 12 education, with 6.2% having a diploma or degree (see Figure 7.6). Most of the tertiary education qualifications had been obtained through correspondence colleges in fields such as business, computer skills or nursing. There were no diplomats or graduates among this sample of rural respondents. 10.7% of

all respondents had only primary level education, with the majority of the under-educated individuals being older women from rural communities.

Figure 7.6: Educational Status of the CPQ Respondents:



7.8.2: Socio-economic context:

The majority of respondents from the nine partnering communities live in conditions of abject poverty, with terribly high unemployment rates, limited access to social grants or health and welfare resources, and extremely poor living conditions.

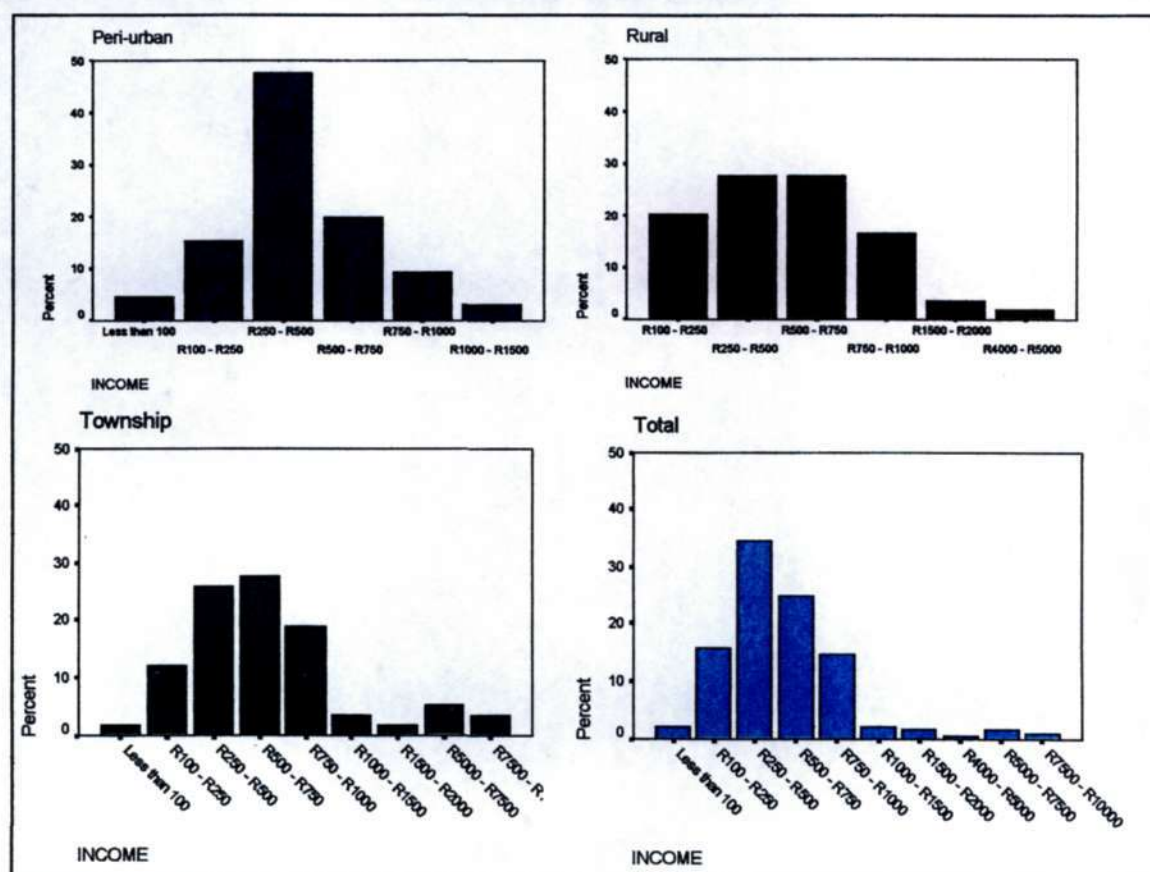
The unemployment rate was extremely high with 80,2% (n= 142) of the respondents being unemployed, 5,1% in casual or irregular employment, and only 5,6% in full time employment. The fact that the SP was run over five working days possibly excluded employed individuals, but there is little doubt that the high unemployment rate was a major characteristic of all nine partnering communities. There was an interesting group of 8,5% who described their employment status under the 'other' category but there is no information available to investigate this further. It is hypothesised that some of these people were volunteers working on community development forums, volunteering in crèches, offering early childhood development stimulation programmes, working in community gardens, offering HBC, and so forth. The employment pattern differed across the geographic regions, in the unexpected direction of 9,3% of rural, 1,5% of peri-urban and 6,9% of the township respondents in full time employment (See Table 7.6). It would seem that those who live in peri-urban areas find it especially difficult to secure employment.

The high unemployment rate is reflected in the low household income levels and the strong reliance on various forms of social grants, especially old age pensions. 52,8% of the respondents stated that the households live on less than R500:00 per month: 2,3% report that barely survive on less than R100:00, 15,9% subsist on between R100:00 and R250:00, and the remaining 34,7% live on between R250:00 to R500:00 per month. At the other end of the spectrum, 3.4% of the respondents had a total monthly household income of more than R4000:00 (these were mainly the traditional leaders and the professionals – social workers and educators - who attended the SP). The geographic distribution again shows that it is the individuals in the peri-urban areas who battle the most in terms of employment and income (See Figure 7.6).

Table 7.6: CPQ respondents' employment status:

	Total	Rural	Peri-urban	Township
Full time employment	5,6%	9,3%	1%	6,9%
Part time or casual employment	5,1%	0	9,2%	5,1%
Unemployed	80,2%	72,2%	83,1%	84,5%
Other	8,6%	18,5%	4,6%	3,4%

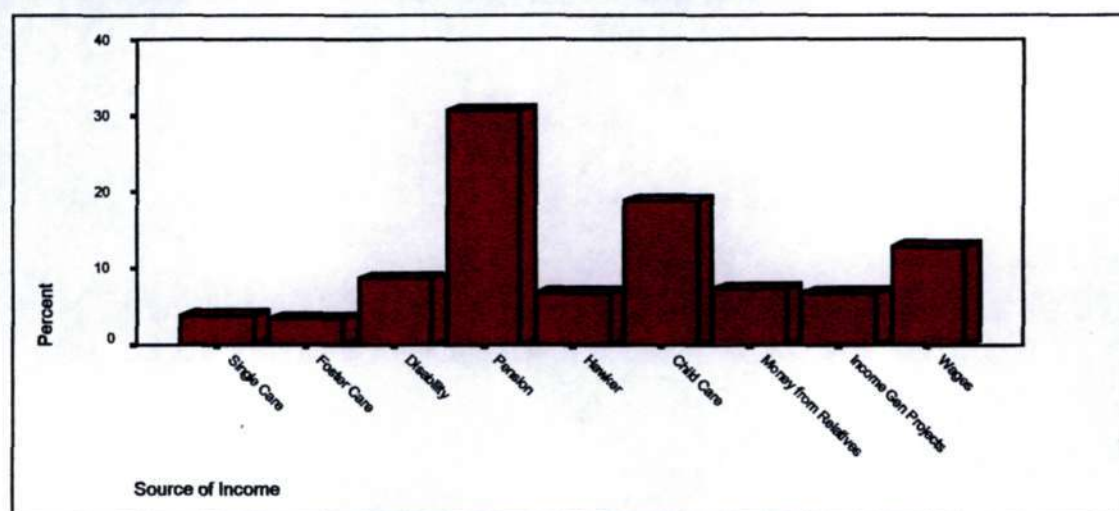
Figure 7.6: Monthly household income of the CPQ respondents:



To grasp the reality of life for the poverty-stricken individuals, one needs to bear in mind that on average there were 8,66 people per household. Extrapolating from these figures suggests that nearly 50% of the people who participated in the SP have a *per capita* income of only R28:86 per person per month (based on R250 per month with 8,66 persons per household). There was abundant evidence of the direst poverty: malnourished and very thin individuals, wearing the same washed-thin clothes to each session, and clearly suffering from their lack of food security, with dermatological problems being especially rife. Under conditions of such dire poverty, one can understand why the catering became a key feature of the programme both for the adult participants in the SP and for the children during the SGTP. Many programme participants would arrive hungry, at times not having eaten for a few days. Many had not eaten a single piece of fruit for years. There were some children who did not even know how to peel a banana, even though banana trees are indigenous to this province! The data collected from the children's primary caregivers confirmed the impact of poverty on children's lives (see Section 5).

Only 39% of households receive salaries, wages or money from income generating projects or from relatives who work in town and send monthly contributions. Most households are reliant on social welfare grants for their subsistence, with 75,5% of the respondents stating that their household received at least one of the available grants. Pensions were the most frequent form of social welfare grant, with the relatively recently introduced child support grant being the second most frequently accessed social grant (See Figure 7.8).

Figure 7.8: Source of household income for the CPQ respondents:



There were variations across the geographic regions in terms of the respondents receiving grants and the type of grants that they were receiving (See Table 7.7). As a generalisation, rural people are reliant on old age pensions and do not seem to be accessing the other grants for which they

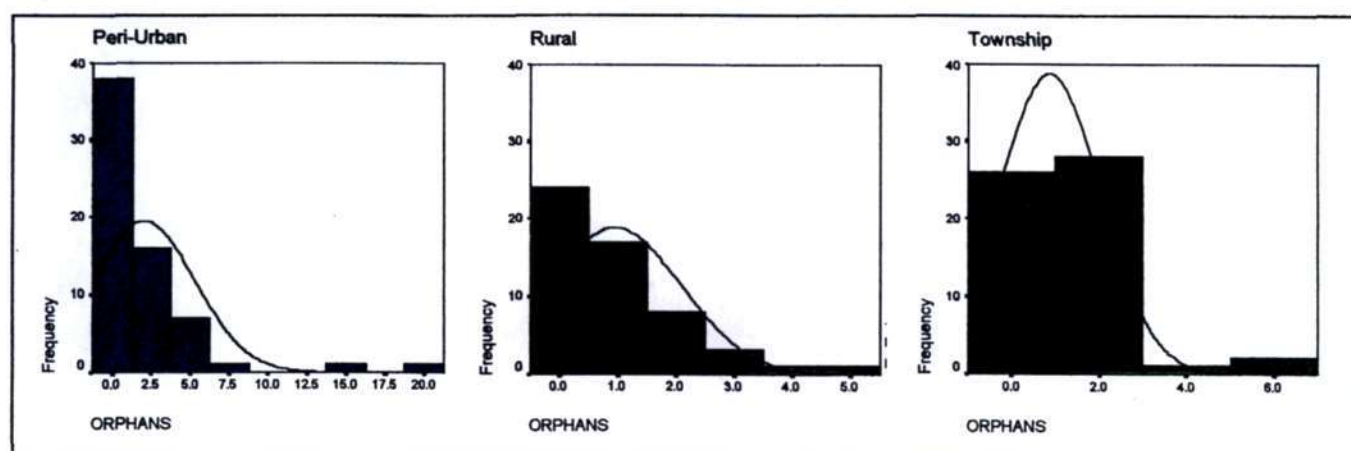
may be eligible. Peri-urban and township dwellers seem to have better access to the childcare and disability grants.

Table 7.7: Access to grants across the geographic regions of the CPQ respondents:

Form of social grant	Rural	Peri-urban	Township	Total
Single care grant	1.9%	7.7%	3.3%	4.5%
Child care grant	13%	26.6%	24.1%	21.6%
Foster care grant	3.7%	4.6%	3.3%	4%
Disability grant	5.6%	13.8%	10.5%	10.2%
Old age pension	41.5%	40%	24.1%	35.2%

Across the three geographic regions, only 21.6% draw the child support grant for children, which was until recently a means-based grant for children under the age of 7 years. The CPQ data shows that 73% of the households in this sample have children who qualify according to the age criteria and presumably meet the means criteria in terms of the high unemployment and low income rates. Likewise, large numbers of people who would on the surface appear to qualify for the foster care grant are clearly not accessing this grant. Although 61% ($n = 107$) of the respondents have orphan/s living in their households, only four percent ($n = 7$) of households were receiving foster care grants (see Figure 7.8 for the number of orphans per household). This is especially an area of concern where households have more than one orphaned child living in their home.

Figure 11.8: Number of orphans per household for the CPQ respondents:



On average, there were 1,3 orphans per household (std dev = 2,234) and a range from no orphans up to twenty-one orphans in one household (all seven of the children born to this grandmother had died and the family now subsisted on the old lady's pension, taking care of her twenty-one grandchildren).

Social workers are required to investigate, report on the circumstances and then conduct extensive follow-up for all foster care grants. This prolonged procedure, in combination with the lack of social workers in many rural and peri-urban areas, may be creating enormous unnecessary and crippling financial burdens on many households. The economic implications of having all individuals receive the social grants to which they are entitled would be enormous in terms of the national treasury and the other demands that are being placed on the national budget for health and educational facilities. Nevertheless, the daily struggles to survive combined with the suffering and humiliation associated with poverty probably constitutes one of the biggest threats to any country's security.

At the other end of the age spectrum, 45% of households had someone over the age of 60 years, with the mean number of pensioners per household being 0,57 (std dev = 0,691) and a range of zero to three. However, only 35,2% of the CPQ respondents indicated that someone in their household drew an old age pension. Cross-tabulating data obtained from the CPQ shows that 64,8% of those individuals (taking into account the number of individuals over the age of 60 years and those households that draw an old age pension) that appear eligible to draw old age pensions do not receive them. More elderly people reside in rural areas, and yet this is the geographic region in which pensioners are least likely to receive these pensions ($\chi^2 = 4.69$, $df = 2$, $p = 0.096$), even though when one considers which grants people in rural areas are accessing, the pension is the most frequently accessed form of social grant. The pattern of age demography, in which the elderly are more prevalent in rural areas, is consistent with the reports from community members that when someone is unlikely to obtain employment, due to either age or illness, they move to the rural communities. Unfortunately this often means that they are then less likely to be able to access their pensions.

10,2% of the CPQ respondents has someone who draws a disability grant (with the most frequently cited reason given as mental retardation). Most mentally (and physically) challenged individuals live with their families who usually take full responsibility for their care, without access to support from state health, welfare or educational resources. It would seem that pensions and disability grants are critically important for the subsistence of many of the respondents.

The basic household infrastructure again portrays a picture of poverty and disadvantage, especially for the rural and peri-urban residents. Just over half (55,7%) of the respondents reside in traditional mud and daub homes, 21,3% live in brick buildings and 21,3% live in homes made

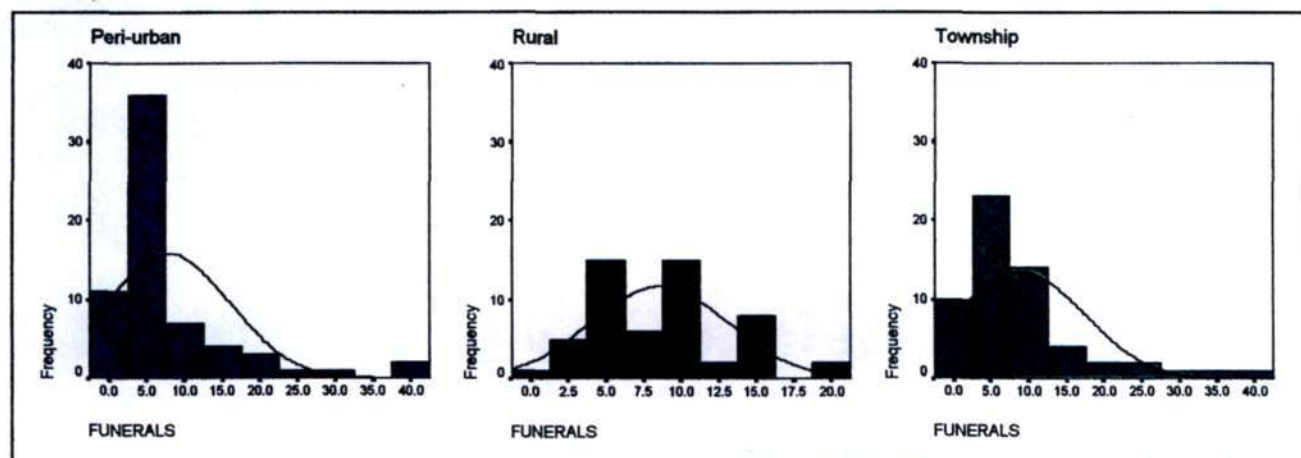
with a combination of bricks, mud and daub. From the total sample, only 1,1% lived in shacks and all of these came from township areas.

7.8.3: SP participants' perceptions of problem areas:

The CPQ asked respondents to indicate problem areas within their community, firstly in the form of an open-ended question and then by indicating from a provided list. The responses to the open-ended questions and the provided list showed much consistency and relatively few categories had to be developed in which to classify the responses across the open-ended questions. The profile of responses is presented in Table 7.5. It would seem that criminality is a problem in all areas, especially in the rural and township areas where theft was the most commonly reported crime. The abuse of alcohol was also a highly prevalent problem. Having insufficient food is clearly poverty related, and the theft rate may also reflect poverty, illness and HIV/AIDS related conditions were rated separately in accordance with the spontaneously mentioned category in response to the given question.

The mean number of funerals was not accurately obtained as many respondents simply indicated that there had been too many funerals. Of those who did respond with a number, they had attended an average of 8,4 funerals over the preceding two month period, with a standard deviation of 7,34 (see Figure 7.9). This would clearly be an under estimate, when one takes into account the respondents who reported 'too many' funerals.

Figure 7.9: Number of funerals attended over the preceding two-month period:



62,7% of respondents recognised that HIV/AIDS was the main cause of recent deaths, with violence, motor vehicle accidents and stabbing also identified as leading causes of death. Most of the respondents had had a family member die of an AIDS-related death, with this mean being 3,47 (std dev = 4,412) (see Figure 7.10).

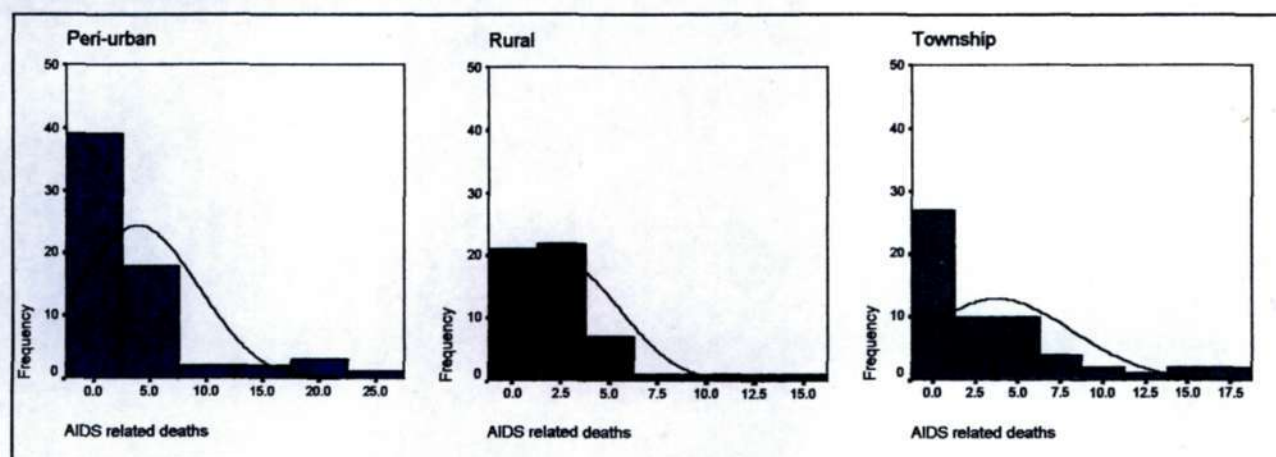
Table 7.8: Most frequently mentioned problems from the CPQ (percentages):

Identified problem	Rural	Peri-urban	Township	Total
Too many criminals	92.6 ⁺⁺	92.3 ⁺⁺	65.5 ⁻	83,6
Alcohol	90.2 ⁺⁺	84.6	69.0 ⁻	81,4
Insufficient food	88.9 ⁺⁺	81.5	63.8 ⁻	78
Illnesses	90.7 ⁺⁺	83.1	60.3 ⁻	78
HIV/AIDS	74.1	84.6	72.3	77,4
Violence	79.6	80.0	67.2	75,7
School problems	70.4	76.9 ⁺⁺	44.8 ⁻	64,4
Dagga and other drugs	55.6	75.3 ⁺⁺	53.3	62,1
<i>uMuthi</i> , Black magic	53.7	72.3 ⁺⁺	50	59,3
Other	74.1 ⁺⁺	60.0	32.8 ⁻	55,4
Child abuse and neglect	46.3	58.5 ⁺⁺	17.2 ⁻	41,2
Too many deaths	45.6	42.3	15.2	34.4

Key + Notes: ⁻ Indicates that there were significantly less ($p < .05$) instances of that community having access to the facility under question than would be expected by chance.

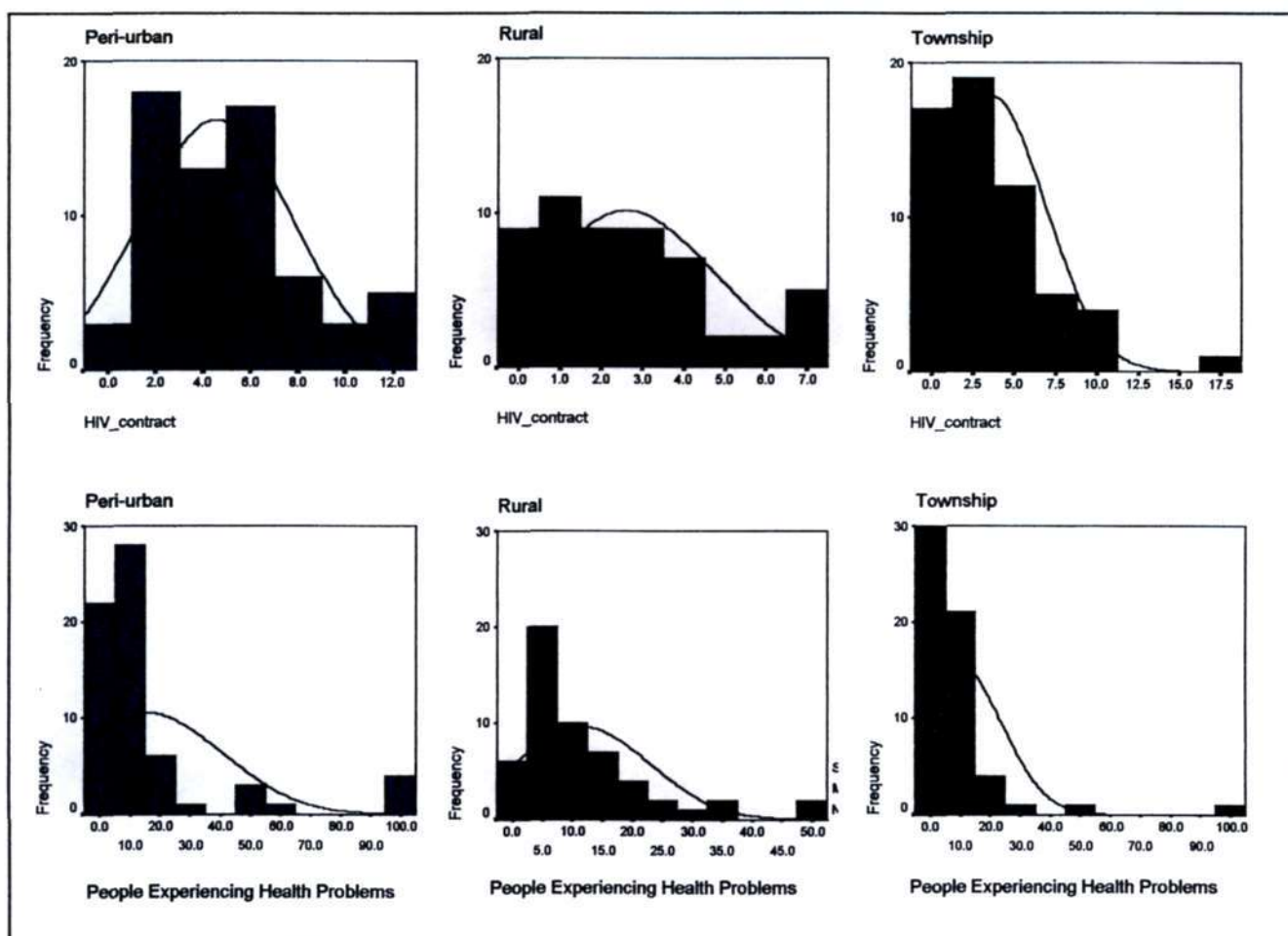
⁺⁺ Indicates that there were significantly more ($p < .05$) instances of that community having access to the facility under question than would be expected by chance.

Figure 7.10: Number of people each respondent knew from their own communities who had died from an AIDS-related condition:



Many individuals are known to be currently suffering from serious health problems, with a mean of 12,4 (std dev = 18,38) people presently known to be ill (See Figure 7.11). A very similar number had people in their family or community were known to be infected with HIV: average of 3,66 people (std dev = 3.02). In general, the positively skewed tail was due to the response patterns in which some respondents said they knew of hundreds whom had died, were ill or HIV+, while others provided a specific number.

Figure 7.11: Number of people currently known to be seriously ill and HIV infected:



7.8.4. Summation

It seems that the major defining characteristic of the nine partnering communities is the extreme poverty in which they live and survive. Despite the fact that many have achieved their grade 12 educational status, the shortage of employment opportunities greatly impacts on their lives and the nature of social problems that beset them. Crime and substance abuse were ranked the most frequently occurring problems in nearly all of the communities, with HIV/AIDS being more likely to be acknowledged within township communities than in the peri-urban and rural communities. Despite the negative circumstances that prevailed in the partnering communities, few had access to the services of NGO's or had formed CBO's. Although most of the respondents were highly spiritual and attended religious services on a regular basis, the churches and other FBO's were not regarded as organisations that work with social problems. There was certainly evidence to suggest that there is no duplication of services within these partnering communities, with there being a dismal paucity of service organisations within all nine of the partnering communities. The most neglected areas were the rural ones, who also seemed to experience the most difficulties in accessing social services and grants.

The nine partnering communities are carrying the burden of extreme poverty with intolerably high unemployment rates, and they are experiencing numerous problems created by the onslaught of HIV/AIDS and other factors that are usually associated with dysfunctional societies. The Bible tells us that "You have the poor with you always" (John:12.8), but the degradation of human life experienced by those who do not have basic necessities nor food security is a problem that needs urgent attention. It is difficult to isolate the causes of the current unprecedented societal stress and suffering. However with the HIV/AIDS pandemic, one can reliably predict an increase in the problems unless steps are taken to intervene and start to remedy the situation. The high levels of community cohesion suggest a way forward in terms of ameliorating these difficulties in a sustainable manner, in that it clear that communities are committed to the well-being of people within their community and are willing to offer help and assistance.

Section IV

The Evaluation of the Sensitisation Programme

In this section, the methodology, results and discussion on the evaluation of the Sensitisation Programme are presented. The overall objective of this research programme was to evaluate the holistic community-based intervention that aims to offer psychosocial support to the vulnerable children affected by HIV/AIDS, poverty and violence. It has thus been imperative that the author situate the context carefully as the partnering communities had specific qualities that may help future users of this programme in deciding if the programme would be applicable within their own contexts.

The focus at this stage, shifts to a more detailed evaluative one, in which the sensitisation programme is subjected to a qualitative evaluation. It is logical to present the methodology, results and discussion of these results in the next two chapters, so that the reader can follow the sequence of ideas for this aspect of the evaluation.

Chapter 8

The first unit of analysis: Methodology

Strengthening capacity in high prevalence HIV/AIDS communities

The first unit of analysis was at the community level. The aim of the research was to consider the effectiveness of the sensitisation programme in sensitising adult community members to the psychosocial needs of vulnerable children and to enable them to offer psychosocial support (PSS) and ameliorate the impact of the risks associated with the HIV/AIDS pandemic. Offering PSS has been identified as one of the most appropriate and accessible means through which communities can be strengthened to support vulnerable children (Germann, 2002; Hunter & Williamson, 2002). The purpose of the SP therefore was to create greater awareness, understanding, compassion and care at microsystemic levels within the partnering communities. Consistent with action research (Patton, 1990), the assumption was made that increased awareness and knowledge of the psychosocial needs of children would motivate communities to offer PSS to their vulnerable children.

In developing the sensitisation programme there was recognition of the fact that all of the partnering communities had faced various hardships including extreme poverty (Richter, 1994) and a history of political discrimination and violence (Dawes & Donald, 1994; Higson-Smith & Killian, 1999). Furthermore, it was presumed that certain children within the partnering communities would have been exposed to especially difficult life circumstances and as such could be regarded as being particularly vulnerable. Consideration of community-based conceptualisations of this and other key variables formed part of the sensitisation programme, so that community members could identify those children whom they regarded as being especially vulnerable. It is important to note that no distinction was made between children rendered vulnerable due to factors directly associated with the HIV/AIDS pandemic and other risks such as poverty, violence, abuse and neglect. Ethical considerations precluded offering an intervention intended only for those children directly affected by or infected with HIV/AIDS.

8.1. The research questions in relation to the partnering communities:

There were three sets of inter-related questions and methodologies with respect to the community level of intervention (See Table 8.1). The major focus of this unit of analysis was on the summative evaluation of the SP, however it was necessary to implement and document the other two aspects of the community intervention and research programme since they were integral to the SP:

1. **Action research** was used to empower community members to acknowledge their own skills

and ability to solve problems in various innovative and appropriate ways at grass roots levels. The research purposes were to (i) form working partnerships between the researcher and community members; and (ii) to make explicit the community conceptualisations of key concepts involved in the programme. The objective of the latter exercise was to enhance the applicability of the programme for the specific circumstances within each community and to develop working definitions of some of the key concepts. Thematic analysis of small group discussions and plenary report-backs provided the data for this aspect of the research.

2. **Formative evaluation** considered strategies to improve the SP and to more effectively respond to the needs of the participants. This was not a major focus for the current study and so brief qualitative evaluations (in the form of comments and descriptions about the day's proceedings) at the conclusion of each the SP training days were considered to be sufficient. Although the programme was being conducted in a standardised manner, the daily evaluations enabled the researcher to ascertain if the implementation process was proceeding according to the prescribed standards as set out in the manual and to rectify any misconceptions that had perhaps developed during the course of the day's training.
3. **Summative evaluation** of the SP on the basis of:
 - *Community profiles* to distinguish between various community types and structures (geographic regions and other demographic variables) in terms of the effectiveness of the SP.
 - *Thematic analysis of the SP* using (i) post-workshop questionnaires and (ii) focus group discussions to evaluate the effectiveness of the SP.
 - *Community driven initiatives* offering PSS were recorded as indicators of whether the SP had achieved its' objective of empowering participants to be willing and able to offer PSS. This was considered a measure of "raised awareness in people of their own abilities and resources to mobilise for social action" (Bhana, 2002, p. 235).

9.2. Action research:

The theory of programme action states that implementation and evaluation are interlinked processes (Patton, 1990). Social reality is integral to social action and social behaviour can only be understood whilst taking social dynamics into consideration (Zaccaro & Marks, 1996). An individual's responses are entirely interdependent with the responses of other individuals (Orasanu & Salas, 1993, in Zaccaro & Marks, 1996). It is the theory of action that links inputs and activities to the outcome measures. In this instance, there were various interlinking processes that served the overall purpose of this study - evaluating the effectiveness of this community-based intervention to offer PSS to vulnerable children.

8.2.1. Establishing collaborative partnerships: An overview

Once partnering communities had been selected, various inter-related activities enabled the researcher to develop collaborative partnerships to strengthen the communities' capacity to offer PSS. An overview of the action research processes through which the researcher engaged with the various communities is presented in the following section. This will be followed by more in-depth descriptions of the methodologies adopted at the community level.

The purpose of the following section is to present the overall flow of the research process. It seems logical to present this as a chronology of the activities (See Table 8.1) before presenting the requisite details of the methodology.

Table 8.1.: Steps in the community intervention and evaluation:

Step	Activity	Intervention purpose	Research purpose
1	Community selection	Commencement or rekindling of a relationship	High HIV/AIDS prevalence, different geographic regions, prior NPO/CBO activity.
2	Community mobilisation meetings (CMM)	Increased awareness of the psychosocial needs of children.	Action research to enable people to solve problems of vulnerable children.
3	Community begin taking action	Empowerment for community to draw on their own resources	Empowerment
4	Sensitisation Programme	SP conducted in each community	Formative evaluation and part of summative evaluation
5	Community driven initiatives & follow-up support	Community driven initiatives: Support and encouragement for community initiatives at regular follow-up meetings.	Community driven initiatives: Record activities as a measure of the capacity building output.
6	Focus group discussions	Empowerment of community members and formation of support structures across communities.	Summative evaluation of the SP.
7	Registers of vulnerable children	Increased motivation and greater organisation.	Children in distress identified for the child intervention.
8	Follow-up meetings continue in tandem with the child intervention.	Community driven initiatives; researcher gives support and encouragement. Shift of focus to the child level of intervention, for some volunteers.	Community driven initiatives. Record activities as a measure of the capacity building output.

Step 1: Selection of partnering communities: The procedure for selecting high prevalence HIV/AIDS communities was described in Chapter 7.

Step 2: Community mobilisation meetings (CMM's): A series of meetings was conducted with community members and key stakeholders in each area. The objective was to make people more aware of the needs of children in the hope that they would resolve to take action, on a volunteer basis, to offer PSS to the most vulnerable children in their communities. The format, number and attendance at the CMM's varied between the different communities (See Appendix C) and does not form part of the current research programme. The purpose of these meetings was community mobilisation, i.e. to develop a degree of consensus that the community needed to take collective responsibility for meeting the psychosocial needs of their vulnerable children. The research method was one of action research - a method acknowledged to be less systematic, more informal and more responsive to specific community level problems (Patton, 1990, p. 157).

Step 3: Communities begin to take action: Resulting out of the CMM's but independent of the researcher, various activities were undertaken to address the needs of children. The researcher attended CMM's to give support and encouragement. The focus for the researcher was on developing relationships, promoting people's confidence and supporting the endeavours. Many activities embarked upon at this stage proved to be needed and effective. Occasionally input was requested and given - this usually revolved around issues of accessing educational and social services in the forms of school fee remissions, social grants and registrations of births, deaths, etc. Seven of the communities decided to engage in income generating projects and/or community food gardens. During this process, it became evident that certain individuals were more ready and able to volunteer their services than others.

When community members began asking for specific input, they were offered the opportunity to participate in the 5-day SP. The community was requested to identify 20 - 30 people who (i) wanted to participate in the training programme, (ii) were likely to become involved in offering PSS to vulnerable children on a volunteer basis and (iii) would be available for the full training programme of five successive days. Community members were asked to arrange suitable local training venues, inform key stakeholders and ensure that participants were informed of the logistical arrangements. The researcher arranged training materials and catering. When this programme dovetailed with pre-existing NPO activities, the responsibility for identifying participants and venues still rested with community members. There was usually a small group of three or four individuals who emerged as

organisers and took primary responsibility for the arrangements before, during and after the SP. This group was not necessarily the same as those people who put energy into activities such as those mentioned above: income generating projects, food gardens or creches.

Step 4: SP conducted in each community: The 5-day SP (Killian et al., 2002; see Appendix D) was conducted in the nine partnering communities with 20-30 people participating from each of the communities. In addition to various other activities, participants in small groups spent time discussing key concepts: health, illness, death, HIV/AIDS, orphans and community during the first day. This data was subsequently content analysed. On the second day of the SP, the programme began by considering the stages of child development and led to a discussion about some children having particularly 'difficult life circumstances' that could place their development at risk. The participants discussed the risk and vulnerability factors to which children in their community were exposed, together with the associated effects and outcomes of experiencing some of the adversities. This procedure afforded the opportunity to develop operational definitions of vulnerable children and PSS. The SP participants were then asked to perform psychodramas of the situations that they felt reflected the emotional and social impact of the risk factors on children. Unfortunately these were not recorded, as it was felt this may impede the spontaneity of the participants. The psychodramas spectacularly portrayed the misery that impacts on many children and served the purpose of increasing awareness of the psychosocial impact of risks on vulnerable children at the community level. Conducting a budgetary process in which participants were requested to allocate fictional amounts of money to meet children's physical, educational, social, emotional and spiritual needs enabled participants to realise that psychosocial needs do not require financial input and that PSS comes from the goodness in people's hearts.

At the completion of each day of the SP, participants evaluated the day's proceedings in order to alert the researcher and co-facilitators to ways in which the SP could be improved or tailored to better meet specific needs of a particular group.

On the final day of the SP, participants were requested to generate plans of action for community initiatives to offer PSS. This enabled them to plan to apply the information covered during the SP. They were also requested to complete evaluation questionnaires on what had been useful, what they had learnt, what had not been beneficial and to give suggestions for improving the programme.

Step 5: Community-based initiatives and follow-up support meetings: On completion of the SP,

participants volunteered time, energy and skills to implement their plans of action to offer PSS. They worked in small groups and kept records of their activities. These initiatives were community-owned and -driven with minimal input from the researcher. Follow-up support meetings were held at regular monthly to six weekly intervals to monitor progress and develop confidence in implementing the community-based initiatives. During one of these support meetings, three representatives from each community were selected to participate in the focus group discussions.

Step 6: *Focus group discussions* were conducted to summatively evaluate the SP. In order to facilitate open feedback and to ensure anonymity, the focus group discussions were conducted by independent researchers. Participants were reassured that the information from the focus group discussions would be kept confidential in terms of individual input and that the discussions would be used to improve the SP for future use in their own and other communities. The writer was not present at the focus group discussions. The focus group discussions also created a forum for the participants to begin to develop inter-community liaison and sharing of learnings and difficulties.

Step 7: *Communities develop registers of vulnerable children in their area.* This formed the first step towards the implementation of the child intervention (SGTP) and served to motivate community members to continue their activities. It was usually at this stage that the SP participants began asking for more specific input about helping children in distress, usually in terms of their concern for specific children living in especially difficult circumstances.

Step 8: *Community driven initiatives and follow-up support meetings continue* and the research focus is widened to include the second unit of analysis: vulnerable children. The volunteers who had been most integrally involved in developing and running community-based initiatives became part of a core group in each community who were offered the opportunity to be trained as research assistants and/or to become apprentice-facilitators for the SGTP or for one of the control conditions.

The development and maintenance of the on-going collaborative partnerships between the researcher and the community members was an essential component of this research programme. PAR principles were consistently used to guide this process. The fact that the researcher and the community actively engaged in this process made the other aspects of the study possible.

9.2.2. The exploration of community conceptualisations of key concepts:

An individual is a social being who actively interacts with society and in so doing is involved in a

process of meaning-making about social constructs (McNiff, Lomax & Whitehead, 2003). The meanings that people attribute to various phenomena are used to make interpretations about the world through which they can make sense of what happens to them and others. It was believed that different cultures and communities may have developed unique and implicit understandings of concepts such as health, illness, death, community and orphans. Since these concepts were integral to the programme of intervention, it was necessary for community members to make these conceptualisations explicit and to become aware of any prejudicial or stigmatising myths held by the group or individuals.

This exercise afforded the opportunity for participants to (i) create shared meaning through group interaction that would enable them to develop working definitions and (ii) make explicit conceptualisations that would have relevance and meaning in their lives. Although a great deal of information dissemination about HIV/AIDS has been undertaken, researchers still consistently report ignorance, stigma and a proliferation of myths (Campbell, 2003; Marcus, 2002). Health, illness and death are concepts that carry physical, emotional and social meaning (Arnold, 1990). Even though there is a body of literature on the constructs of community (Duffy & Wong, 2000), orphans (Giese et al., 2003) and risk and vulnerability (Dawes, 2000), the researcher needed to ensure that there was a shared meaning attributed to these constructs by those who would be offering PSS to vulnerable children. People needed to actively engage with and express their understanding of these key constructs. During this process, the researcher developed insight into community definitions and conceptualisations that could then be used as the starting point for further sensitisation and confidence building.

By the time that the participants were asked to discuss these key concepts, they were usually familiar with the researcher as she had been participating in the CMM's and had conducted the informal survey to establish if the criteria for selecting a partner community had been met. The participants of each SP were asked to consider cultural and community definitions of key concepts within small group formats. In each instance the facilitator introduced the topic, small groups discussions took place and then a spokesperson for each small group presented their responses at a plenary feedback meeting. On the first day of the SP, the concepts health, illness, death, community and orphans were discussed. Vulnerability/risk and PSS were explored on the second day. The group discussions and presentations were the critical arena through which typical phrases, metaphors, arguments and stories came to the fore to enable the researcher to gain insight into the participants' understanding and attributions about these key concepts (Terre Blanche & Durrheim, 2002).

9.2.2.1. Health, illness, death, community and orphanhood:

The facilitator of the SP introduced the task of discussing multi-cultural understanding by first writing on the flipchart (See Figure 9.1) and then using the example of health saying:

"In my family, community and culture, people are considered to be healthy if they are hardly ever sick, if they do a lot of physical exercise, if they do not smoke and do not drink alcohol. In some communities, people are considered healthy if they do not have any aches or pains. Health may be thought to be caused by the absence of germs, the season of the year (people are more likely to get coughs and colds during certain months of the year), or by various other things. The consequence of being in good health is that someone can do many things like work, be active, play soccer, etc. A healthy person is not sick."

The researcher stressed that there were no right or wrong responses as each community, and even family, had their own specific ways of dealing with any of the concepts. Participants formed small groups of five to eight individuals, selected one of the concepts (ensuring that all topics were covered) and then considered the ways in which the concepts were defined and understood by people in their own community. Examples were not provided for the other key concepts. Each group was asked to elect an orator and to prepare notes on a flip-chart to present to the plenary group. They were allotted thirty to forty minutes for the discussion. The groups then reconvened for plenary report feedbacks. At the end of the presentation, others were encouraged to contribute their own ideas.

Figure 9.1. Community-based definitions of key concepts:

<u>Community Definitions</u>
In our family, community, culture and nation we understand / know / think about Health / Illness / Death / Orphans / Community as ... What is it? What is health / illness / death / orphans / community? Why or how does it happen? When does it happen? What are the consequences of health / illness / death / orphans / community. Only choose <u>one</u> concept to discuss!

Special attention was given to observing non-verbal communications. The most frequently noted non-verbal communications were either signs of affirmation and agreement or dissent (nodding and shaking of heads). Disagreement at times took the form of frustration, which was dealt with by

encouraging the individual to voice his or her opinion and open it to debate. Some interesting debates took place that enabled the researcher to gain insight into the intensity of affective involvement in the concepts. Due to the sensitive nature of some of the topics, co-facilitators were requested to take special note of individual reaction to the tasks and to later, individually and in private, enquire if the individual needed extra assistance to deal with difficulties. To conclude the session, the researcher said that she would be using the inputs to analyse the community-conceptualisations, but as an interim measure, she attempted to arrive at a summary or definition of the concept for the purpose of the workshop and the work that would follow. The SP participants usually continued to engage with these concepts as they arose in the programme and frequently asked to add a further component or to modify a concept that had been previously discussed. This was encouraged since the active engagement and thinking on the concepts were key outcomes.

The flipcharts and notes made during the plenary session were used to develop the community-based definitions. In this manner nine sets of text were obtained on each of these concepts that could be analysed further.

8.2.2.2. Vulnerable children:

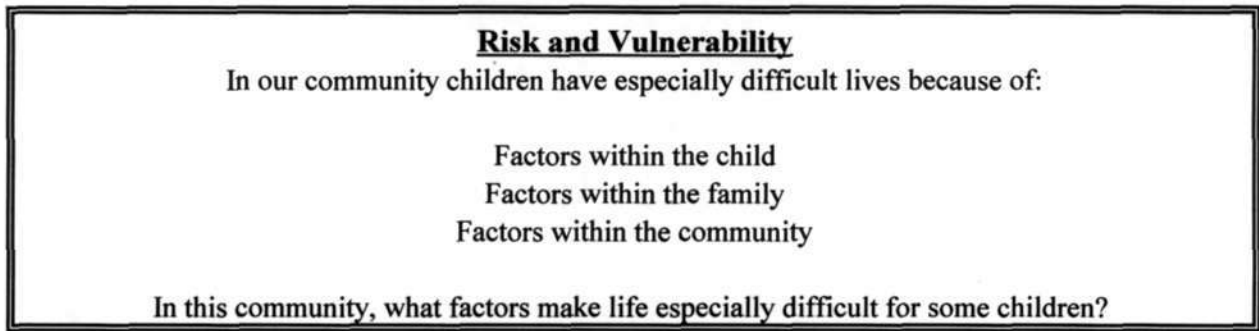
On the second day of the SP, community members were asked to discuss the concepts of risk/vulnerability and PSS. While making notes on the flipchart (See Figure 8.2), the facilitator introduced the topic by stating:

"Nowadays, many children are having especially difficult lives. Their lives may be difficult because of situations that arise within the child - for example the child may be mentally retarded, blind or may find it difficult to live comfortably with others. A child may find life difficult because of situations that arise within the family. For example, the child may have parents who drink too much, who fight, whose family members who are sick and dying or whose parents work far away. Or the child may have an especially difficult life because of the situation in the community, such as lack of resources, no jobs, lots of deaths and so on."

The participants were divided into small groups of five to eight participants (with different group compositions to preceding activities) and asked to discuss the concept of vulnerability/risk and to develop a working definition of a vulnerable child. Again, they were asked to elect a group orator who would provide feedback at the plenary session. They were given thirty to forty minutes for each discussion and more time if this seemed to be needed. The spokesperson then presented their ideas in the plenary session, followed by contributions from other participants. The same procedure as discussed above in Section 8.2.2.1. were used to encourage debate and to develop a working

definition of vulnerable children.

Figure 8.2.: Causes of risk and vulnerability for children in this community:



8.2.2.3. Analysing the community inputs:

The small group discussions enabled the researcher to tap into the constructed reality of meaning associated with these concepts (Zaccaro & Marks, 1996). The procedure that was adopted has some inherent disadvantages: pressure from the group to conform, the need for group cohesion, fear of expressing a divergent perspective, normative constraints and gender-based role definitions. Nevertheless, group discussions were considered to be particularly well suited to stimulating discussion around issues about which there are implicit, commonly-held understandings and an absence of clear explicit definitions. The dynamic nature of the discussion enabled the researcher to capture ideas as well as the paradoxical ('yes ... but ...') nature of the concepts (Kriel, 2001). The synergistic effect of the group discussions resulted in the production of knowledge as there was an opportunity to express both shared knowledge and important differences. This method of collective generation of knowledge (Bhana, 2002; McNiff et al., 2003) enabled exploration and description that aimed to enhance subjective, contextual and cultural understanding of the concepts. There are no claims to the generalisability of this data.

It is important to note that these were not focus group discussions in the usual sense (Kelly, 2002). Participants conducted their own discussions with the facilitator and co-facilitators wandering between groups to deal with any queries that arose. Very few queries emerged and the discussion was usually quite lively and animated with most participants feeling comfortable to actively enter the dialogue. The researcher noted the pervasive presence of gender differences in that men tended to take more prominent roles in the discussion and the presentation, while women were more likely to need encouragement to become spokesperson for their small groups. This trend was less evident by the end of the 5-day SP. In fact by this stage, many participants had surprised themselves by being the spokesperson and speaking in front of the large group, amid much self-proud and cheering

from others.

The advantage of this technique over the usual focus group format was that the participants could express themselves freely in their home language and debate could take place before a degree of consensus was reached. The main purpose of this activity was to encourage the participants to reflect on these concepts, and not to collect data. The reflective process was then incorporated into the rest of the SP, and was extensively used during the period when the community was offering psychosocial support through their own initiatives and when the SGTP was being conducted in their areas.

In the instances in which consensus was not fully reached, i.e. when a discrepant point of view was held by one or two of the participants, the various perspectives were either presented by the group's spokesperson or by the individuals concerned. Women appeared to be more reluctant to express discordant views. This was primarily an action research exploration (McNiff et al., 2003), when people were encouraged to focus on the way in which they understood the concept, the associated categorisations and form a collective position in terms of the most pertinent aspects of the concepts. The procedure had the disadvantage of losing the actual words that participants had used, so that the social construction of meaning could not be ascertained. On the other hand, the advantages were considered to outweigh the disadvantages, and to adequately serve the purpose of enabling community members to actively engage with the concepts that were critical to offering PSS to vulnerable children. The main purpose at this stage was to sensitise the participants to the psychosocial needs of children and as such this aspect of the research can be considered to fall within the spectrum of action research.

The contents of the presentations as well as the contemporaneous notes were transcribed and translated. Transcribing the discussions and the contents of the flipcharts were time-consuming processes through which text was created to facilitate analysis. Some editing of the text (especially when written in basic English) was necessary in order to maintain meaning. This editing was kept to an absolute minimum so as not to change the character of the constructs (Stewart & Shamdasani, 1998). After transcribing, the translation process began. Input from the co-facilitators (*isiZulu* home language speakers) was especially useful in this regard as they had frequently gained a better sense of the group reaction to the plenary report backs. The translations were subjected to discussion and debate until consensus had been reached that the translations were as accurate as possible. However, most qualitative researchers would concur with the current researcher's experience that transcription

and translation are highly complex processes requiring patient, persistent attention to detail.

The purpose of the thematic analysis was to explore and describe the community-based conceptualisations as part of an action research process (Reaves, 1992). The data collected in this instance represented an amalgam of perspectives and as such was idiosyncratic and had ecological validity (Stewart & Shamdasani, 1998, p. 506). It enabled unstructured and qualitative data to be transformed into categories that led to the identification of explicit and implicit themes within a structured framework. The explorative and descriptive objective was for both the participants and the researcher to gain insight into the communities' conceptualisations.

Thematic analysis usually begins with pre-defined themes that have been identified through a review of the pertinent literature (Reaves, 1992). However, the researcher did not want to rely on literature-defined themes but rather to see what emerged from the participants themselves. All text pertaining to each of the concepts was included in the analysis. Therefore, after the transcriptions and translation, the first step required the identification of the units of analysis. These were defined as the words and phrases that reflected conceptually distinct ideas (Krippendorff, 1980).

These were then transcribed onto separate notelets, with the origin of each unit of text being written on three different colour notelets to indicate rural, peri-urban and township groups. The use of the different colour pens enabled tracking of community input (with nine colours being used, one for each community). The memos were then stuck on the walls where they could be repeatedly arranged and rearranged into cognate groupings or themes that provided an overview of the various ideas associated with each of the concepts. Discussion between various researchers and colleagues led to ascribing labels to interpret the groupings that could then be rank ordered on the basis of their frequency of occurrence. This enabled the researcher to see which aspects of a concept were (i) considered to be central and critical components of each of the constructs; (ii) less prominent in the community conceptualised the construct; (iii) specific to particular regions, forms of communities, or specific circumstances; and (iv) not included, but on the basis of the related literature or western-notions, could reasonably have been expected to be introduced. The results of this analysis are presented in the following chapter.

8.3. Formative evaluation of the SP:

Formative evaluation is the process of undertaking evaluation research aimed at on-going programme development (Terre Blanche & Durrheim, 2002, p. 478). Responsiveness to participants' needs is

fundamental to both programme implementation and evaluation. In this instance, the formative assessment had two primary objectives: (i) Working with people created the ethical obligation to continuously monitor the impact and adapt the programme, if necessary, to uphold ethical principles; and (ii) to identify aspects of the programme that worked well, were problematic or required improvement (Potter, 2002). Programme implementation is a dynamic, bi-directional process in which constant feedback and learning creates awareness of the participants' needs and reactions. Pilot implementations of this programme (outside of the scope of the present study) had enabled the authors (Schoeman et al., 2000) to remedy difficulties and improve the programme to the point where a summative evaluation of a standardised version of the SP could be undertaken. However, in practice standardised administration is only partly attainable. A skilled facilitator makes adjustments to meet the dynamic needs of participants. The apprentice-facilitators had to be trained to respond effectively to changing group climates and needs. At the end of each day, participants were asked to evaluate the proceedings in terms of both their positive and negative experiences. This also afforded the researcher the opportunity to reinforce learnings, correct any misconceptions and to tailor the next day's programme in accordance with the feedback. The research ethic of PAR required careful consideration of all evaluative inputs. Consequently, there were minor shifts in focus across communities.

This process also enabled the researcher to monitor the implementation of the programme. As Patton (1990) so rightly states "unless one knows that a programme is operating according to design, there may be little reason to expect it to produce the desired outcome" (p. 105). Implementation evaluation needs constant attention to inputs, activities, processes and structures (ibid.) so that even though implementation evaluation is not usually a part of formative evaluation, it seemed to comfortably slot in at this level of the intervention. In terms of the implementation evaluation, all partner communities were exposed to essentially similar administrations of the SP. Formative evaluation was not a prime focus of the research programme and so no specific results pertaining to the formative evaluations are presented. The formative evaluations required immediate response. Suggestions to improve the programmes are presented in Part V of this dissertation.

8.4. Summative evaluation of the SP:

Effectiveness is defined as the positive effects or success of an intervention as measured in real-world contexts as opposed to rigorously controlled situations (Terre Blanche & Durrheim, 2002, p. 447). Summative evaluation endeavours to establish the outcome and impact of the programme by measuring specific criteria that reflect the effectiveness of the programme (Shaprio, 1999). As such, programme development and programme evaluation are closely linked procedures (Potter, 1999;

Robson, 2002) since in developing a programme one aims to address specific difficulties and problems, and to expect particular outputs. The main objective was to enable participants to gain a better understanding of the psychosocial needs of vulnerable children and to become motivated to offer PSS. It was hoped that with deep and rich understanding, community members would feel compassion towards vulnerable children and be sufficiently confident and enskilled to take action on their behalf by initiating activities, that had a PSS component, for children in their communities.

The summative evaluation of the SP took into consideration four measures: (i) community profiles to determine if community structure and demographic variables influenced the effectiveness of the programme, as presented in Chapter 7 above; (ii) qualitative analysis of the SP on the basis of post-workshop evaluation forms; (iii) focus group discussions on the effectiveness of the SP; and (iv) records of community-driven initiatives that offered PSS to vulnerable children.

8.4.1. Qualitative analysis of the SP:

Qualitative evaluation of the SP took place through (i) the participants completing an evaluation questionnaire at the conclusion of the SP; and (ii) focus group discussions with three groups of SP participants each including representatives from the three geographic regions. The transcriptions from the focus groups and the evaluation questionnaires provided the body of data for the summative evaluation of the SP, together with the records of community-based initiatives offering PSS to vulnerable children.

8.4.1.1. Post-workshop evaluation questionnaires

All of the SP participants were requested to complete the evaluation forms (See Appendix F) during the penultimate session of the SP. The questions were presented in English and *isiZulu*. Respondents completed the form in their language of choice - 94% chose to complete the questionnaire in their mother-tongue, *isiZulu*, 63% of these added short notes of thanks or praise to the researcher in English. In some instances, participants required assistance in completing the form due to their relatively low literacy. This did not seem to precipitate embarrassment and was readily accommodated by either another community member or by the co-facilitator. The responses were anonymous, with no space being provided for the respondents' names. Forty to sixty minutes were allocated to complete the evaluation form. Most participants seemed to sincerely appreciate the need for open and honest feedback to enable improvement of the course for subsequent community groups.

The problems associated with this form of evaluation include (i) the immediacy of the feedback

possibly meant that the positive energy generated during the course would effect the feedback; (ii) it did not give participants time to reflect, outside of the SP forum, on the course before providing feedback; (iii) the researcher was present (though disengaged) during this process and by this time, she enjoyed good relationships with nearly all of the participants with the result that they may have been more inclined to give positive feedback. Cumulatively, these disadvantages could have created a positive slant to the data. It was therefore necessary to combine this feedback with data obtained using a strategy that would obviate these problems. Nevertheless, the information was considered useful and was thematically analysed along similar lines to the procedure outlined in Section 8.2.2.3, with greater reliance being placed on data obtained during the focus group discussions.

8.4.1.2. Focus group discussions:

Focus groups seemed the most appropriate modality for interviewing participants about the effectiveness of the SP (Schensul, LeCompte, Nastasi, & Borgatti, 1999; Stewart & Shamdasani, 1998). The purpose of the focus groups was explained to the SP participants at a follow-up support meeting as being an important part of careful and extensive evaluation of the SP, that would inform decisions about whether it was an effective means of meeting the needs of the community, if it should continue to be offered and to get ideas about how it might be modified or improved.

The researcher wished to select three participants from each community to form focus groups of nine individuals with three people from each of the different types of regions. Quota sampling was used to select the focus group participants. After explaining the purpose, the participants were asked to indicate if they were willing to participate in the focus groups that would take place at the university on a Sunday morning. These people then wrote their names on provided slips of paper that were then placed in a box. Amid much cheering, three names were drawn from the box by one of the community members. The composition of the three focus groups is presented in Table 8.2. The groups were formed in such a way as to enhance both homogeneity (3 people from a single community to provide support and a sense of safety to express concerns and conflicts) and heterogeneity (in terms of geographic regions) as a strategy to stimulate and enrich discussion (Robson, 2002). Four people (of the 254 people who participated in the SP) did not wish to be part of the focus groups, as they had recently experienced family deaths and traditional practice precludes family members visiting town during the month subsequent to the death.

The focus groups were conducted by an independent researcher for the purpose of yielding an independent audit. Participants were informed of this at the time that logistical arrangements were

being made. Her role was explained as an impartial evaluator whose task it was to ensure the anonymity of the participants while getting sincere feedback about what had and what had not worked during the SP. There was no need for a translator to be present as she is mother-tongue *isiZulu* speaker. The researcher was not part of the focus groups in order to enable the participants to give feel free to give honest feedback about any difficulties that they may have experienced.

Table 8.2.: Composition of the focus groups:

Descriptors of the participants in the focus groups to evaluate the SP.	Focus Group 1	Focus Group 2	Focus Group 3*
Rural community.	3	3	3
Peri-urban area.	3	3	3
Township area.	3	3	3
An area with a prior NGO activity.	6	3	6
Participants from a CBO.	3	6	3
SP conducted by the researcher.	6	3	6
SP conducted by an apprentice-facilitator.	3	6	3
Subsequently became an SP or SGTP apprentice-facilitator.	7	6	6
Male participants in the focus group	3	2	4
Total number of participants in focus group discussion	9	9	9

* Problems were experienced with the transcription of this focus group, see Section 8.4.2.2).

The focus groups took place nine to fifteen weeks after completion of the SP. Participants were given refreshments on arrival and before departure. The focus groups were audio-taped. The independent researcher took notes during the session in order to formalise the meeting and as back-up in case of problems with the taping. The introduction for the focus group discussions and the interview schedule are presented in Appendix I. It was hoped that the focus groups would enable participants to feel sufficiently empowered to critique their own experiences, stimulated by thoughts and comments of others in the group (Robson, 2002). Generalisability of results emanating from focus groups is usually limited (*ibid.*) but it was felt that this technique would serve the major purpose of the study. One of the benefits that the researcher had hoped would emerge from the focus group constellations was for participants to acknowledge the unique circumstances of their own communities as well as the commonalities across different communities. It was believed that inter-community interaction would begin a process of networking between communities. This outcome was achieved and further opportunities for inter-community conferencing of successful initiatives and sharing of difficulties

have been arranged for the partnering communities.

8.4.1.3. Qualitative analysis of the data on the summative evaluation of the SP:

The goal was to elicit data on the effectiveness of the SP. The thematic analysis was intended as a rigorous method that emphasised reliability and validity of the results (Stewart & Shamdasani, 1998). The audiotapes were carefully transcribed, with the assistance of the facilitator's notes. At first, a single experienced translator (who had not been present at the focus groups) was used to translate the transcriptions from *isiZulu* into English, without the intermediary step of first transcribing into *isiZulu*. This procedure was found to be problematic when the translations were checked by the writer and the independent researcher who had conducted the focus groups. It appeared that the research assistant was placing his own interpretation on some of the phrases that were not readily translatable from *isiZulu* into English. Once this problem was identified, a six-day workshop was convened. The focus group facilitator, the research assistant and three participants (one from each focus group discussion, selected on the basis of fluency in *isiZulu* and English and successful completion in the research data collection training that formed part of the SGTP evaluation) took part in this workshop. All understood the need for strict adherence to the content of what had actually been said. They were also requested to sign a further pledge of confidentiality to ensure that they understood that the information was to be kept confidential and that should they realise the identity of particular respondents, these would not be disclosed. These five individuals worked through the audiotapes and the facilitator's contemporaneous notes from the time of the focus group discussions to arrive at English transcriptions that as accurately as possible reflected what had been said in the focus groups. They were requested to minimally interpret ideas, metaphors and concepts. The procedure was to (i) listen to the tape, (ii) halt the tape after input from each focus group participant, (iii) each then independently wrote their own translation of the input, (iv) share and discuss the various translations, (v) arrive at a translation in accordance with majority thinking, (vi) re-listen to the tape to check that the statement had indeed been accurately translated, and (vii) revise the translation if necessary and in some instances, begin the process again until consensus had been reached that the input had been accurately captured. This process required close repeated listenings to the recordings. The purpose of including the focus group participants had been to ensure that the data remained rooted at the grass-roots level. It was not an attempt to arrive at 'respondent validation' (Silverman, 2000, p. 177) since the task was simply to translate and transcribe. It was a means of establishing consensus from two people (the focus group facilitator and one community member) who had been present at the focus groups and three who were new to the specific discussion and so less likely to be biased by their own interpretations.

The use of translated, transcribed text from audiotapes enabled the researcher to obtain actual details of one aspect of social life, to have the transcripts available for public scrutiny, and to inspect the sequence of utterances (Silverman, 2000, p.149). This method of deriving text provided an accurate account of the focus group discussions for the purpose of enhancing the validity of the analysis (Hammersley, 1990, in Silverman, 2000). The need to obtain accurately translated transcriptions required some creative problem solving. However, it also created a problem in that one of the tapes (already of a poor quality with much background noise) became so stretched that the conversation was incomprehensible, even when various technological strategies were used to screen out background noise. The researcher had little faith in the initial translated transcription from focus group 3, even though it was consistent with the themes that emerged from the other two focus groups, so greater reliance was placed on the first two focus groups in the analysis.

It also became evident that group dynamics had played a role in determining what happened during the discussions, with some evidence of rivalry being evident. In addition, several focus group participants spontaneously commented that they perceived it to be an honour to participate and believed that they were representing their community group. In hindsight, this may have influenced them to present mainly positive information even though numerous attempts were made to elicit the weaknesses or challenges inherent to the SP.

Therefore in an attempt to overcome these difficulties, a further focus group was conducted using a different sampling technique. From a pragmatic perspective, it was deemed expedient to conduct one further focus group within a specific community. All the participants in this group were from a rural community where they had completed the SP six weeks previously. A different independent researcher and translator facilitated this group (neither had been involved in the SP previously). This process was however less than satisfactory as the transcription indicated that some questions had been asked in a leading or suggestive manner and the text appeared to be more facilitator than participant-based. These factors suggested that some of the rules for conducting a research interview had been inadvertently transgressed (Robson, 2002). Therefore, this transcription was used for the purpose of applying the refutability principle, for the constant comparison method, and to examine for deviant cases (Silverman, 2000).

The thematic analysis took part in two stages: (i) the researcher applied three techniques to identify the major themes and (ii) two independent researchers were asked to derive themes on the basis of the text alone. This procedure allowed greater validity and since the external audit that was purely

data driven, it enabled inter-rater reliability to be established.

In the first stage of the thematic analysis, the researcher conducted an initial reading to systematically consider all possible meanings of the transcribed text (Reaves, 1992) for the purpose of identifying implicit and explicit meanings (Krippendorff, 1980) and to provide the first thematic categorisation. Secondly, using a process from thematic analysis (Silverman, 2000), sequences of related talk were identified, analysed for thematic content and listed. Thirdly, it seemed that some text-units were repeatedly mentioned so word frequency counts were conducted on these as they had the potential of being exemplary statements to demonstrate central meaning (Gillham, 2000; Neuman, 1997). The themes derived using these three techniques were then compared to arrive at a revised provisional categorisation of the data. The entire data set was then coded with the objective of being able to attach codes or inferential labels to the concepts. Viewing the data embedded in the original holistic text called for some refining of the themes. The coding of the data enabled the researcher to breakdown, compare, conceptualise and categorise in a meaningful manner to ensure that the patterns of understanding and their exceptions were identified (Strauss & Corbin, 1990). The transcripts were again read with the goal of identifying all units into the themes that could then be meaningfully interpreted. As predicted by Terre Blanche and Kelly (2002), the process of identifying themes was difficult since during the process of coding, themes evolved and changed, necessitating frequent review of the entire process.

Throughout this process, the researcher attempted to be inductively data-driven in order to effectively respond to the research question. Identifying themes was regarded as the most essential aspect of the content analysis. Since "the categories contain the substance of the investigation, a content analysis can be no better than its system of categories" (Berelson, 1952, cited in Robson, 2002, p. 355). Therefore, much effort went into trying to accurately identify the themes. The researcher at first tried to derive categories that were exhaustive and mutually exclusive, however this created two problems: (i) there was a 'dump' category (Robson, 2002) of text that did not comfortably fit into other categories; (ii) most comments were interrelated and interdependent. The researcher then consulted with two 'blind' research colleagues who were given the transcriptions and asked to thematically analyse the transcriptions. One was asked to begin with Focus Group 1, while the other was requested to begin with Focus Group 2. Neither of these blind researchers were informed of the nature or purpose of the SP, but were asked to let the data speak for itself. The two researchers arrived at similar themes to those that the researcher had originally identified. This process therefore served to increase the researcher's confidence in her analysis and to give an

indication of inter-rater reliability. The next stage involved defining the central themes, with their supporting concepts, in diagrammatic form and a further cross-checking was undertaken to ensure that the diagrams accurately reflected what had actually been said and meant.

8.4.1.4. Capacity building within the communities:

One of the primary objectives of this research programme was to develop capacity within communities to offer PSS to their vulnerable children. Action research, and in particular PAR, has empowerment as a primary goal (Collins, 1999). PAR is a form of participative, person-centred enquiry that does research with people (Heron, 1996), while aiming to empower them through the process of constructing and using their own knowledge (Reason, 1994). Research within this framework is not only a process of knowledge creation, but simultaneously develops awareness in order to help people to mobilise for action (Gaventa, 1988, in Collins, 1999). The ultimate measure therefore of the effectiveness of the SP was to be found in what happened within each community when the researcher was ensconced in her office at the university. The creation of real change requires the empowerment of people to be better equipped to deal with their daily struggles (Tandon, 1988, in Collins, 1999). Empowerment was measured in terms of (i) community responsiveness as reflected in the activities undertaken on behalf of vulnerable children; and (ii) the development of confidence and capacity in people who volunteered their time, energy and goodwill to assist vulnerable children in their area subsequent to participating in the SP.

Before developing plans of action on the last day of the SP, participants were asked to adhere to a set of rules that would govern any initiatives that offered PSS to vulnerable children: (i) Always work in small groups of three or more (for the protection of individuals and children); (ii) Inform and obtain consent from family members and the children; (iii) All information revealed to them by children or family members had to be kept confidential between group members and the researcher in order to stringently avoid gossip; and (iv) All activities had to be properly arranged with accurate record keeping. At follow-up support meetings, community members were asked to discuss their progress, or lack thereof, any learnings or difficulties that had arisen and their future plans. People arrived at the follow-up meetings with records of activities, eager to give feedback about what they had achieved. They usually produced evidence of their initiatives in the form of registers, photographs, memory boxes, story books, children's art works, and so on. The role of the researcher was to provide encouragement, support and input if it was needed or requested. The most frequent requests for additional input were on how to obtain social welfare grants and on issues pertaining to child sexual abuse. These meetings continue on a regular basis. Their purpose is to give support

and strengthen community members to offer PSS to vulnerable children (Hunter & Williamson, 2002).

The other measure is an anecdotal indication that includes self reports from volunteers who spontaneously reflected on the meaning of the programme for them personally and for their communities. The anecdotes from various professionals and leaders on the progress made by the volunteers is a further indication of confidence building. Since these are simply anecdotal in nature they are included in the Appendices, but served to confirm the value of the programme at a highly personal level for those individuals who spontaneously submitted letters of thanks or reports about the impact of the programme on their lives.

Chapter 9

Results and discussion

Strengthening capacity in high prevalence HIV/AIDS communities

The aim of this chapter is to discuss and present the results of the programme evaluation at the community level of analysis. Consistent with the purposes of the research programme (See Table 7.1), there are two focal areas: (i) to provide commentary on the *action research methodology*, firstly as a strategy for intervention and secondly, in creating working definitions and making explicit the community-conceptualisations of key ideas in offering PSS to vulnerable children; and (ii) to present results of the qualitative *summative evaluation* of the SP with respect to the post-workshop evaluations, the focus group discussions, and the capacity building components. The action research methodology, the community conceptualisations and the post workshop evaluations will be commented on only briefly as they lacked the methodological rigour of the other aspects of the community analysis. Although they form an integral aspect of the overall intervention programme, in terms of the summative evaluation of the SP, they need to be understood as having a supplementary role, which was nevertheless, critical to the overall implementation and evaluation of the programme.

9.1. Commentary on the action research methodology:

The research ethic recognised that there are no “quick-fix solutions ... [but it is] by patiently and persistently working our way through our dilemmas of social living that we come to situations that ... hold promise for the possibilities of a better world” (McNiff, Lomax & Whitehead, 2003, p. 2). By adopting an ethic of PAR, community members were integrally involved in conceptualising the problems faced by vulnerable children. The problem formulation phase has been recognised as one of the most difficult aspects of action methodology (Collins, 1999). At a fundamental level, all interactions between the researcher and the partnering communities (adults and children) had to be based on power sharing, equality and participation (Plaut & Landis, 1992). Time and energy were invested in creating the collaborative partnerships that formed the foundation on which this programme was built (Reason, 1994; Simpson, Wood & Daws, 2003). The challenge was to select, enter and mobilise communities in a manner that facilitated an emancipatory approach to knowledge production, sharing and utilisation (Bhana, 2002; Mulenga, 1994). People, who had frequently been the victims of social exclusion, needed to play active roles in collectively investigating the circumstances of their community, in understanding the adversities that they and their children were facing, to have sufficient belief in the programme to invest social capital (Fraser et al., 2003) and to feel adequately empowered to offer PSS to vulnerable children.

The fact that the researcher was well known within six of the communities proved to be a clear advantage. In the other three communities, people were offered the opportunity to obtain character references on her from those who had known her for years. The leaders from the three newly acquainted communities took the opportunity to confirm the credentials of the researcher. There is little doubt that establishing credibility at grass roots is a critical initial step in any intervention and/or research programme (Simpson et al., 2003). People who have been oppressed and disenfranchised are slow to trust and tend to work at their own rhythm (Meintjes, 2004). They have learnt to be especially suspicious of research agendas. The time and energy needed to develop personal relationships within each of the communities made the initial progress frustratingly slow. Nevertheless, it is believed that the single most significant contribution to a successful community intervention lies in the formation of collaborative partnerships within the context of trusting, respectful interpersonal relationships (Meintjes, 2004).

Although the community entry and mobilisation processes are not primary focal areas in this research, they formed the foundation upon which the intervention programme was based. It is therefore necessary to briefly comment on some of the factors that seemed to be particularly important. The purpose of the community selection, entry and mobilisation was for key community-members to recognise that (i) some of their children were experiencing especially difficult lives, and (ii) the community needed to collectively take responsibility for these children. The number and form of the community mobilisation meetings [CMM] varied across communities (See Appendix B). The community development forums, the local *Amakhosi*, youth groups, CBO's, NGO's, FBO's and community members took responsibility for these CMM's. The researcher was usually treated as a guest at these meetings with little input being solicited by the meeting organisers. The topic of discussion at the CMM's was focussed on children - their needs and difficulties in the present times. The researcher was frequently drawn into conversation through comments of the "remember when we ..." variety, when they recalled the hardships of the era of political violence and extreme poverty that was characterised by the lack of basic infrastructure and turbulence. It is believed that since the researcher had previously been involved with projects pertaining to political violence, her presence at the meetings slanted the discussion towards this longitudinal or chronosystemic (Bronfenbrenner, 1986) view. From the communities' perspective, the function of this approach seemed to reinforce the notion that this new onslaught of hardship originated from sources external to the community. The stigmatisation associated with the HIV/AIDS pandemic leads people to adopt this position. It also functioned to establish connection between the researcher and community members by

creating a sense of shared history and experience, thereby promoting the equality of these relationships.

From the early stages of the programme in each community, it became apparent that relatively small groups of individuals (ranging from 3 - 12 people) became especially interested. From this core group, subgroups of two to six individuals took on active roles of (i) making logistical arrangements, (ii) attending most CMM's (or they sent apologies), (iii) being the first spokespersons during plenary sessions, (iv) taking primary responsibility for the community initiatives, (v) becoming research assistants and apprentice-facilitators for the SGTP. At times, these people were already in leadership roles (for example, chairperson of the local community development forums or secretary of a youth group), and at other times, these people simply found the project had personal appeal and relevance.

Beyond this small core group, there were some individuals who attended several of the CMM's. It was not possible to get accurate attendance registers at the CMM's, since people tended to arrive at different times and to wander into and out of meetings. It was common practice for people to write down the names of friends and relatives on circulating registers for the purpose of ensuring that these people who were actually absent would be included in future activities. A total of 254 people participated in the SP across the nine communities representing three geographic regions (as described in Chapter 7). Attendance at the CMMs was not predictive of who would participate in the SP and who would engage in community-based initiatives to assist vulnerable children. Of the people who attended the SP, 37.55% had previously attended three or more CMM; 26.12% had attended two CMM; 22.86% had attended only one CMM; and the remaining 13.47% had not attended any CMM before participating in the SP. Although there was a general trend for a core group to play an active role from the early stages of the programme, some of those who never attended any CMM's, became active only during or after the SP, or when the community-based initiatives were in progress.

The pattern that emerged in terms of attendance at CMM and later participation in the SP did not seem to differ substantially across the regions, NPO/CBO activity, age or gender. Although not accurately documented, the organisers of the CMM (*Amakhosi*, development forums, youth groups, etc.) did not seem to affect either the attendance or subsequent participation in the SP (See Appendix C). Rather, it appeared that some individuals accepted the concept of offering PSS positively and then demonstrated their commitment through regular attendance and participation. The factors that motivated people to offer PSS to vulnerable children on a volunteer basis were the subject of a parallel research endeavour (Gothan, 2003).

One of the desired outcomes of the CMM was for partnering communities to develop and implement appropriate and manageable strategies to address the psychosocial needs of vulnerable children. These strategies were community-owned and driven with the researcher playing a supportive role. At times, apparently well formulated strategies that appeared to be eminently actionable from the researcher's perspective, enjoyed little actual support and failed to materialise. On other occasions, the communities' democratically agreed on projects appeared to be too ambitious, yet worked well as they enjoyed grass roots support. The basic learnings that derive from this phase of the research programme are as follows: (i) One needs to respect the power of collective decision-making to get individuals to commit to their plans of action. (ii) Researchers need to accept and encourage community initiatives putting most of their energy into developing supportive and collaborative relationships (Aggleton & Warwick, 2003; Lev-Wiesel, 2003; Phiri et al., 2001; Plaut & Landis, 1992;). Community workers, during the early stages of a programme, should not be too project or activity focussed (Meintjes, 2004; Simpson et al., 2003). Yet, community owned and driven initiatives have a greater likelihood of being effective and sustainable when dedicated, trustworthy community workers support them. The focus for community workers needs to be maintaining genuine trust in the communities' ability to make decisions and to deliver on their plans of action, even during the times that they experience difficulties (Collins, 1999; Mann, 2002).

9.2. Community-based conceptualisations of key concepts:

The participants had suffered numerous adversities, two of which required special consideration. Firstly, the *apartheid* regime had been designed to create 'apartness', such that the premise that South African communities, as with most African communities, have a collectivist culture where the well being of the group is considered to be a paramount concern, may no longer be a valid assumption (Higson-Smith & Killian, 1999). It was therefore necessary to challenge participants to consider their definitions of 'community' with a view to encouraging or re-establishing a 'sense of community cohesion' between the participants. Secondly, the HIV/AIDS pandemic is defying people's ideas about health, illness and death. The SP provided the opportunity to discuss these critical concepts in a manner that enabled participants to make explicit their worldview and to grapple with the changes that have been imposed through the HIV/AIDS pandemic and years of *apartheid* rule. One of the major purposes of adopting action research methodology was to enable participants to discuss and explore these aspects of their life experience in the hope that by validating and reframing, they would feel empowered to take greater control of their circumstances and more actively determine their future (Plaut & Landis, 1992). Action research methodologies include popular forms of knowledge derived from

personal experiences and other 'non-scientific' ways of knowing in everyday life (Fraser et al., 2003). Although these forms of knowledge lack generalisability (Patton, 1990), they can ultimately turn out to be the data upon which people act and through which change can occur.

The concepts explored in the SP were health, illness, death, community, orphanhood and vulnerable children. SP participants were divided into small groups of between five to nine people and asked to consider the cultural/community understanding of the selected terms (See Figure 9.1 and 9.2). Each small group selected one of the concepts for discussion: on the first day, the choice of topics was health, illness, death, and community; on the second day, all small groups were asked to consider risk/vulnerability, and to operationally define "vulnerable children" (See 9.2.2). The thematic analysis was based on the notes made by each group and the plenary feedback sessions. The concepts primarily reflect consensus opinions, i.e. most SP participants supported the viewpoint. Divergent perspectives were captured, especially if they seemed to be views commonly held by various subgroups (for example, rural women, young people, etc.).

9.2.1. Health:

63 people participated in nine small group discussions on the concept of health. All groups began their descriptions of health by specifying good nutritional status as the foundation on which health is defined. Good nourishment was regarded as enough food, a balanced diet and the intake of the necessary proteins and vitamins. While township and peri-urban groups were more aware of the need for fruit and vegetables, rural groups emphasised the need for meat. Inadequate food supply was considered to be a major impediment to health. The converse, being overweight, was considered to reflect wealth and the presence of health, with only a small group of township youth being aware that obesity could reflect physical problems such as diabetes or high blood pressure.

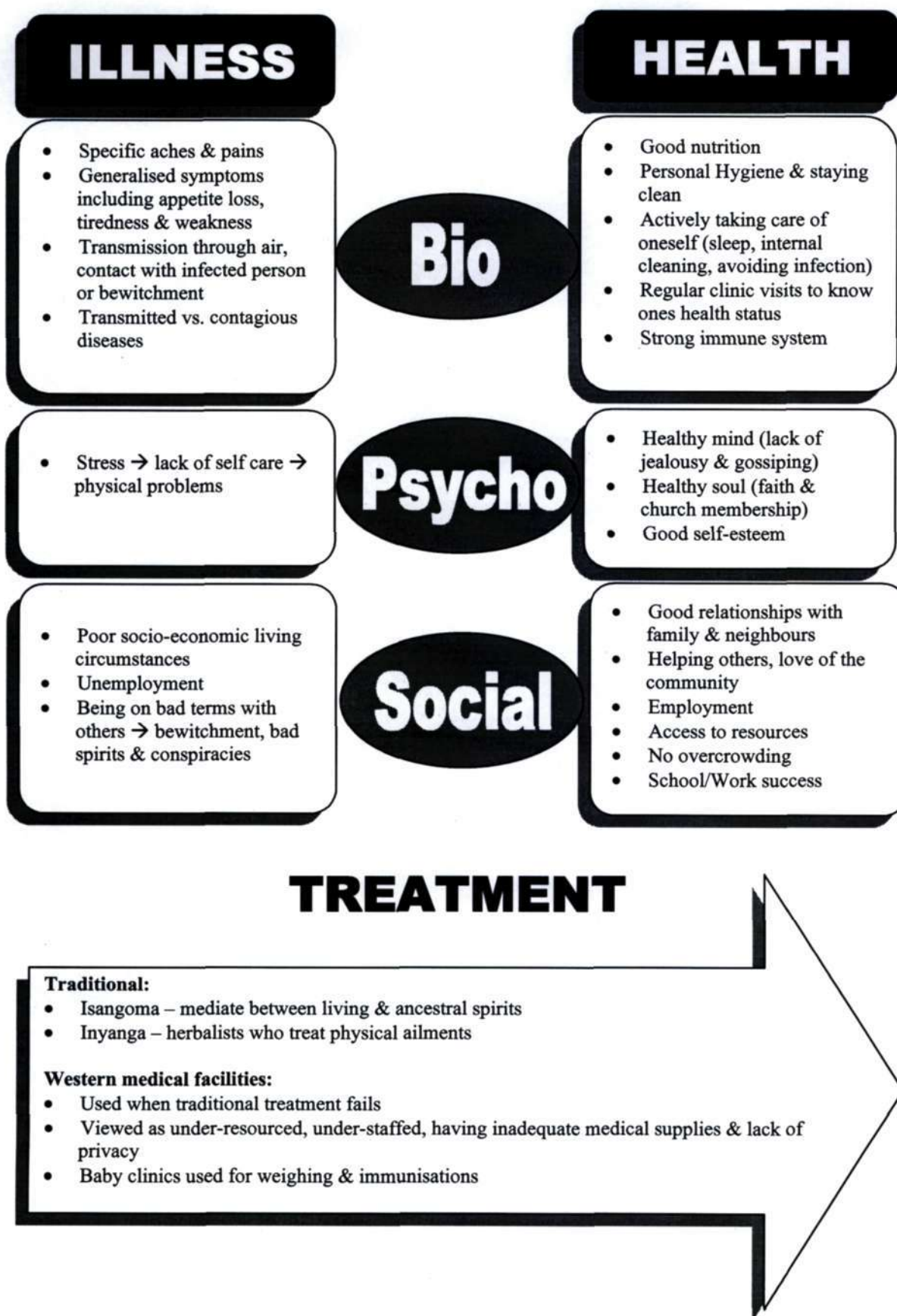
Beyond the consensus that health is equated with good nutrition, there was much agreement on other criteria. It is not possible to differentiate these themes into mutually exclusive categories as there was much inter-dependence between the elements. The other elements associated with health are therefore simply listed in rank order in terms of the frequency of their occurrence in the various discussions (See Figure 9.1):

- *Personal hygiene and staying clean* included the need to wash regularly, brush teeth, and wear clean clothes.
- *Actively taking care of oneself* by getting sufficient sleep, keeping clean internally by avoiding constipation and avoiding contact with sick or unhealthy people. Among those

who spoke of the need to avoid contact with sick people, there was the belief that many diseases are infective and contagious. Rural community members were especially likely to regard HIV/AIDS as highly infectious.

- *Taking care of one's "mind, body and soul"* incorporates the concepts of a healthy mind (e.g., by not allowing oneself to be jealous, to gossip about others, or be revengeful) and a healthy soul (e.g., by placing one's faith in God and/or going to church). *Good self esteem* in terms of self-respect, high achievements and playing a positive role in one's family and community was also mentioned in six of the communities.
- *Being on good terms with one's family and neighbours* are an important aspect of obtaining and maintaining health in two forms. Firstly, peace of mind is created when one does not need to worry about what might happen as a result of being on bad terms with others. In the rural communities, this was associated with knowing that one was then less likely to be the subject of *umuthi*, black magic or bewitchment. Secondly, being on good terms enables access to support, especially in times of difficulty. Participants from peri-urban areas placed greater emphasis on for social support than those in rural or township areas.
- Having the ability, and perhaps even the obligation, *to help others* appeared to reflect a belief that being healthy carried a responsibility towards others who were less fortunate. *"A healthy person always has the love of the community, loyalty towards the people and is friendly towards the people"* (Peri-urban C2). *"Healthy people have to help others that are not so lucky"* (Township, C3).
- 55% of the presentations included the *absence of illness or disease* as a criterion of health. This criterion was usually presented in a flippant manner followed by laughter from the group as a whole. This could indicate that the absence of illness was considered either as an obvious criterion that did not need mentioning (a position that was confirmed only by the younger members of the township communities), or that this criterion was regarded as a poorly thought-out conceptualisation. In four of the communities where this was mentioned, older people objected, as they did not see health and illness as opposite ends of a single dimension. They seemed to rather perceive health and illness to be two different, though related, concepts. They used a bio-psychosocial model of health to support their view. As a community stalwart from Peri-urban C1 stated: *"You may be sick or dying, but if you have a healthy soul and mind, and people respect you, then you are healthy"*. Her community group spontaneously applauded her comment.
- *Having work and money* at one's disposal was a criterion for health in approximately half of the presentations. The emotional intensity relating to this was obvious in that many strongly agreed that you could not be healthy if you were unemployed. Older individuals

Figure 9.1: Community conceptualisations of health and illness based on the data analysis:



did not regard health and employment as related preferring their bio-psychosocial perspective to a model in which one variable is isolated.

- *Access to resources* was regarded as a necessary pre-condition for health. Accordingly, having access to education, roads (not dusty or water eroded), transport, health and welfare services, clean water, agricultural products (cattle, chickens and vegetable gardens), energy in the form of electricity, safety and security (with controlled crime levels) and recreational facilities were perceived as integral to health. It was also considered to be beyond the ability of individuals or communities to provide these. Although this perspective was never phrased in the form of human rights, it is consistent with human rights perspectives maintaining that access to resources is integral to health.
- Approximately a quarter of the participants regarded *regular visits to the clinic* for immunisations, VCT, or general check-ups as a means to exert control over one's own health. Clinic visits enabled one to know one's health status. Diagnosis of health status included, but was not limited to one's HIV status. Participants also mentioned the importance of being medically diagnosed for conditions like TB, hypertension, diabetes, malaria, asthma and STI's.
- Two of the township groups linked health to a strong immune system. This was understood as the body's ability to protect itself from infection. Information provided on HIV prevention had been the basis on which these groups understood immunity.

Some factors arose in only one of the community discussions. (i) Longevity was considered an indication that the old person had lived a healthy life and thus had the ability to set a good example to others. (ii) Overcrowding was associated with ill health. (iii) Success in school or work leads to improved health.

There are some interesting aspects to the way in which these communities conceptualised health: (1) Most of the partnering communities have no food security. The rate of malnutrition is visibly high, especially among children. The concept of 'living positively' is rather hollow, when there is no food security and no opportunity to ensure that one maintains a balanced diet (Guthrie, 2003; Loudon, 2002). The western perspective of improving one's health through adequate nutritional intake, regular exercise and so forth did not resonate with community members who were struggling to survive and get food. (2) Health was considered to be largely outside of one's own locus of control. Health is possible when one is fortunate enough to have access to good nutrition, employment, money and basic resources. As a consequence of the high unemployment and poverty rates, combined with lack of access to resources, large sections of the population

may regard themselves as unable to achieve health. This finding is consistent with psychosocial theories about the impact of poverty (Fraser et al., 2003; McLoyd, 1998). Macrosystemic interventions are needed to address the lack of basic human rights and provide access to resources that were perceived to be integral to health. (3) Health was perceived as having physical, emotional, social and spiritual dimensions. These community conceptualisations are consistent with the World Health Organisation's (2003) definition of health (a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity). 78% of the participants recognised bio-psychosocial components of health, with greater focus on social and communal aspects (e.g., being on good terms with others, being helpful and having an obligation to help others less fortunate than oneself). It is also interesting to note that health is associated with helping and being on good terms with others, a point of view that is consistent with the communal philosophy of African cosmology (Mkhize, 2004) and one that augurs well for community empowerment endeavours.

9.2.2. Illness and disease:

67 people discussed the concepts of illness and disease. Illness was considered to have physical, social and emotional components. The **physical constituents** of illness took the form of aches and pains that were either located within specific regions of the body (e.g., in one's tummy, limbs or head), or generalised symptoms (e.g., loss of appetite, tiredness, feeling weak, and not being strong enough to do work). Physical illness could be transmitted through the air, contact with an infected person, or through bewitchment. People acknowledged having little understanding about the mode of transmission of illness, and generally felt confused about the information at their disposal. Many of the rural and peri-urban participants found it particularly difficult to trust diagnoses based on blood tests since many believed that once blood leaves one's body, it changes and/or can no longer be considered to be a part of the person. There was a suspicion that the spirit of the person holding the blood vial contaminates the blood. Although most had heard about germs, viruses and bacteria were unfamiliar concepts. About four out of five SP participants had never studied biology at school, therefore much of the information disseminated about transmission of disease was neither trusted nor understood.

There was one exception to the above conceptualisation of illness. One township group classified illness into two types: those that are transmitted (e.g. HIV, syphilis) and those that are contagious. They describe transmitted diseases as those that are passed from person to person, some can be treated, while others lead to death. Contagious diseases are described as curable and are caused by lack of hygiene, untidy environment, polluted water, sharing of utensils, and poor sanitation (Township C1). This group of predominantly younger people had a higher standard of

education and could assimilate biological information more readily. They also seemed better able to understand the immune system and the manner in which blood tests are used to diagnose illness. Many of these young people had access to television, and the television programme "Survivor" was repeatedly raised in the debates about the concept of immunity, as some felt that this programme portrayed a concept of guaranteed protection, whilst others felt that it had confused them greatly.

The **social constituents** of illness were similar to those raised in connection with health. They were reflected in poor socio-economic living circumstances, being unemployed, being on bad terms with others, and having others wishing one ill-health or having *umuthi* used against one. In all three geographic regions, there was a strong belief that many people became ill through bewitchment, bad (ancestral) spirits and conspiracies. Most conspiracies arose from feelings of jealousy. Jealousy and envy seemed especially likely to be evoked if someone did well financially, and then either behaved arrogantly or did not meet the responsibility to assisting those less fortunate. Under these conditions, one could consult an *Umthakathi* who would assist in making *umuthi* to harm or destroy someone perceived as problematic. These views were held across all of the geographic regions, including the better-educated township youths.

Stress was the most frequently mentioned **emotional component** of illness. The symptoms of stress were identified as tiredness, irritability, and lack of concentration, poor memory and anxiety. It was considered to be unlikely that stress would manifest in physical symptoms. If stress was prolonged, the communities thought it could lead to lack of self-care that in turn could ultimately result in physical problems such as headaches, tummy aches and weakness in the limbs. This aspect of ill-health was frequently raised spontaneously by community members at later stages in the SP. Women in particular seem to have a strong cultural injunction not to dwell on their negative feelings and as a result many admitted to keeping distressing events to themselves. As the SP proceeded, they experienced the intense relief of sharing feelings and experiences with each other, with several people saying that it this was the first time that they had been able to discuss especially distressing or traumatic events and the subsequent experience of having a burden lifted from their shoulders once they had been able to talk about their feelings.

Being ill required one to rest, and seek treatment from either a western health practitioner at a local clinic/hospital or a traditional healer. Two types of traditional healers were identified: (i) *Isangoma* have the ability to mediate between the living and the *amadlozi* (the ancestral spirits). *Isangoma* can convey the wishes of the deceased to the living so that the cause of symptoms can

be understood. (ii) *Inyanga* are traditional healers who diagnose and prescribe various herbal and natural medicines. Bereaved children who cannot settle after the death of loved ones would most likely be taken to an *Isangoma* who would *"speak nicely to the child and help him or her to understand that the dead person had joined the ancestors"* (Rural C3). Whereas a child who was suffering with physical pains was more likely to be taken to an *Inyanga* than to the clinics. Most children would only be taken to western medical facilities if the condition deteriorated or was unresponsive to traditional intervention. The exception to this general rule, is when infants and young children are taken to baby clinics for weighing and immunisations. It is important to note though that resorting to traditional medical practices was seen as a necessity by nearly half of the people who felt that western services were under-resourced, under-staffed (especially in terms of sensitive or sympathetic staff) and had an inadequate supply of medicines. Clinics were associated with long queues, prolonged waiting times and lack of ventilation. The lack of privacy (in the waiting rooms and not from the health practitioners) afforded in many clinics was also a strong deterrent for many individuals. It was generally agreed that men are more likely to seek traditional and western treatment, while women mainly seek treatment for illness associated with pregnancy and childbirth.

One group noted that *"a person can be attacked by a disease and this happens at any time and people do not plan to be ill but others pretend to be ill"* (Peri-urban C2). This is an example of personification of illness, but also indicates the possibility that someone may fake illness, perhaps for secondary gain.

9.2.3. Death and its associated practices:

It was a formidable task for some community members, especially those younger than about forty-five years to discuss death. Interestingly, older individuals seemed to regard death as an important topic for discussion, stating that people need to change their *superstitious beliefs and not be afraid of death*" (Rural C3). Many participants believed that by discussing death *"one invites death to come to you or your household"* (Rural C1), or *"If someone is very sick and dying, and you talk about death, then that someone will think that you want him dead"* (Peri-urban C2). Once the researcher realised that this was a commonly held belief, she gave participants the option of moving to a different group or selecting to rather talk about the customs that are to be followed when someone dies. The rationale given for discussing customs was that with the increase in deaths, it is important for children to have an accurate cultural perspective on death (what it is, why it happens, what to do). This rationale was usually discussed along the lines that many people, and not only the children, no longer knew the correct rituals and their meanings. Twelve people (4.7% of SP participants), all individuals who had

recently experienced the death of a loved one, elected to shift to a different small group discussion. All chose to participate in the discussion on community.

55 people participated in small group discussions on the topic of death, where the atmosphere was considerably more serious than for the other topics. The phenomenon of death seemed to create a sense of both respect and fear. These groups were offered the additional support of a co-facilitator during the discussion phase. Frequently, these participants used lunch or tea breaks to engage in further discussion with either the co-facilitator or with the researcher. It seemed that the intensity of emotion evoked through discussing death, led participants to seek additional support and/or created a sense of connection with those who were facilitating the course.

This was the only topic in which the communities chose to respond to the questions in accordance with the provided structure (See Figure 9.1). In response to the question of what death is, most communities (8 of the 9 communities) differentiated between natural and unnatural deaths. The following responses to the question "What is death?" were presented in relation to natural deaths (rank ordered from most to least frequently mentioned):

- Departure of the spirit: *"the spirit leaves the body"; "when someone goes to stay with the ancestors", "God comes for the person", "the house in Heaven is finished", "the amadlozi decide and come for take them to join them"*. These phrases were repeated frequently.
- Universality and unpredictability of death: *"It is a natural phenomenon that happens without notice", "Death does not choose, it happens to everyone", "God comes for all of us when he decides it is the right time", "The time will come for everyone, but we don't know when will be our last day", "Sometimes we know when it will come but most of the time we will be taken by surprise"*.
- Physical indicators: *"When the person stops breathing", "When someone is relieved of all pain"*. The heart stopping was not mentioned by any group as an indication of death.
- Inheritance: *"A person leaves his belongings behind", "Now all the belonging are to pass onto someone else"; "Their clothes and money can be distributed."*
- Powerlessness over death: *"Death comes whenever it pleases, we don't know", "Death comes when you least expect it", "Death is like a thief, it can come anytime, and you can't stop it", "Even if the person is old and has been sick, death just comes and you can't control it"*.
- Unacceptable and painful: *"If someone dies from an illness, it is not right", "Whenever someone dies, people feel sadness and pain", "Death is neither acceptable, friendly nor*

easy to get used to”, “No-one’s death is ever accepted”, “Even if it was bad person, it is hard to accept a death”.

- Sense of abandonment: *“When somebody we love leaves us”, “When someone we love chooses to go to God”, “We are left behind”, “The person we love, just leaves us”.*
- Being a victim to death: *“It is a thief that comes to take away our loved ones”.*

In response to the question of why or how death happens, participants again distinguished between (i) natural deaths caused by heart attacks, strokes, tuberculosis, pneumonia, and other illnesses; and (ii) unnatural deaths caused by some illnesses, violence, motor vehicle accidents, dog and snake bites. When asked to specify which illnesses led to unnatural deaths, the responses were HIV/AIDS and other STI’s, alcohol-related illnesses such lung or kidney problems, and *umuthi*-induced illnesses. Natural deaths were uncomplicated, even though they were painful and hard to accept. People knew what had to be done and what happened to the spirit after a natural death. When a person died a natural death, then funeral rites proceeded according to traditional or Christian customs, with many people choosing to follow a combination of practices. A family death creates enormous economic pressure: funerals are vastly expensive; death is usually associated with loss of much-needed income, even if the income was an old-age pension or grant; customs that need to be followed increase the financial burden (e.g. the purchasing and slaying of animals, feeding mourners and purchase of tombstones). Many community members make financial contributions towards funeral costs. After a death, families reconfigure to change responsibilities, make arrangements for childcare, and disperse the belongings of the deceased. The three rural communities were especially concerned about preserving the belongings to meet the children’s current physical needs and they showed a greater awareness of the child’s need to have mementoes of loved ones. Peri-urban and township groups seemed unaware of the need to consider children’s needs when dispersing belongings of deceased relatives.

Unnatural deaths are highly complicated, as people seemed undecided about what would happen to the deceased’s soul, as well as the correct ways in which the bereaved should and could behave. The confusion pertaining to unnatural deaths created many emotional, social and spiritual difficulties for the community members. The most significant factor in this regard appeared to be the shame and embarrassment brought about by various unnatural causes of death, including HIV/AIDS, alcohol induced deaths, suicide and some criminal deaths (murder, gang-related activities, etc).

The various explanations provided by the participants are presented in the form of an integrated narrative in Table 9.1. The validity of this constructed narrative has been checked with seven of

the community groups during follow-up support meetings. They consider it to be a valid (only face validity is being asserted) portrayal of their dilemmas following an unnatural death.

After the session when HIV/AIDS was discussed and efforts made to destigmatise the disease, people from all but two (township) of the communities, spontaneously expressed relief at the thought that maybe the *amadlozi* would not punish those who had died of AIDS-related conditions. It is critically important that people be assisted to form accurate conceptualisations about the how HIV is transmitted and to realise that many HIV infected people are moral, good, upstanding individuals.

Table 9.1: An integrated construction of the dilemmas associated with unnatural and AIDS-related deaths:

Firstly, one needs to understand how the individual is always considered to be a representative of their family. When an *isiZulu* person shakes hands in greeting, he/she does not greet you as an individual, but as a representative of his/her family, and you respond and greet as a representative of your family. Therefore, even in a very simple gesture such as a greeting ("*Sanibona*"), there is evidence that an individual is never perceived as being simply an individual. Rather each individual is always a representative of their family, their roots and their culture. In the same manner, everything that an individual does and does not do, reflects on his or her family. For example, if a child behaves badly, it reflects on the whole family, and is not perceived as simple naughtiness in the child. Likewise when an adult behaves well or immorally, this reflects on the family as a whole and not on just the individual.

Unnatural deaths need to be understood within this context. Occasionally, an unnatural death results from an act of heroism. For example, a person may be killed for a good cause or for the good of many people. However, most unnatural deaths occur because of unacceptable lifestyles in which the deceased exposed him/herself to unacceptable risks by living immorally or mixing with criminals, warlords, and so forth. Death resulting from sexually-transmitted or alcohol-related illness, or suicide and some murders bring shame not only to the individual but to the entire family and their ancestors, and to the community as a whole.

AIDS-related deaths therefore create enormous stress: if you are seen to accept them, then it could be perceived that you support an immoral lifestyle; if you reject them since you reject immoral behaviour, then you are seen to be heartless. This confusion leads to enormous emotional, social and spiritual difficulties, before the death, at the time of their bereavement, and for a long time afterwards. Community members anguish over what they should do. One way out of the dilemma is to give everyone a different cause of death (TB, gastroenteritis or asthma were mostly frequently mentioned), especially at the time of death so that funeral rituals can proceed. This is done, even if it known that the person was HIV+ and died an AIDS-related death, because then the burial can take place and mourning can begin. But the bereaved are left with lots of worry, as they sometimes know the truth, but it is considered better to lie and at least give a decent burial.

Many people also stated that they needed to be given guidance by religious, traditional and political leaders in terms of what are the correct and acceptable responses in these circumstances. Furthermore, many felt that the information dissemination campaigns had merely added to their dilemmas by sexualising HIV/AIDS and making it seem like a sickness that affects immoral people.

The death-related customs usually exclude children, as people wish to protect children from the harshness and finality of death. Many participants recalled their own childhood experiences of feeling excluded, worried, confused or angry about the manner in which they were kept away or lied to at the time of family deaths. For example, it seems that children are often told that the deceased has gone to Johannesburg. The participants recalled their own childhood anguish as they waited for the deceased to return, and their sense of abandonment when this never happened. Another common practice is to have an elder in the family, usually a woman, whisper into the child's ear while they are sleeping that someone has died. This is done in the hope that the information will then gently filter into the child's awareness. Many participants (young and older) reported that they have followed this custom. Each evening before the funeral, they whisper in the sleeping children's ears, and pray for them, so that by the time the funeral occurs, the children would know that the person had died. They also reported feeling angry and frustrated if the children then still persisted in asking questions about the deceased and the funeral.

Community members are acutely aware that AIDS-related deaths that occur at home are especially difficult for children who witness the severe physical debilitation associated with this illness. Death, from an AIDS-related condition, is regarded as highly unpredictable. Even when a person seems close to death, seemingly miraculous recoveries can occur, before the person's physical condition again deteriorates. This is an extremely confusing time for families, placing them on a roller-coaster ride of despair and hope, feeling victims of this mysterious, stigmatising disease.

9.2.4. HIV/AIDS:

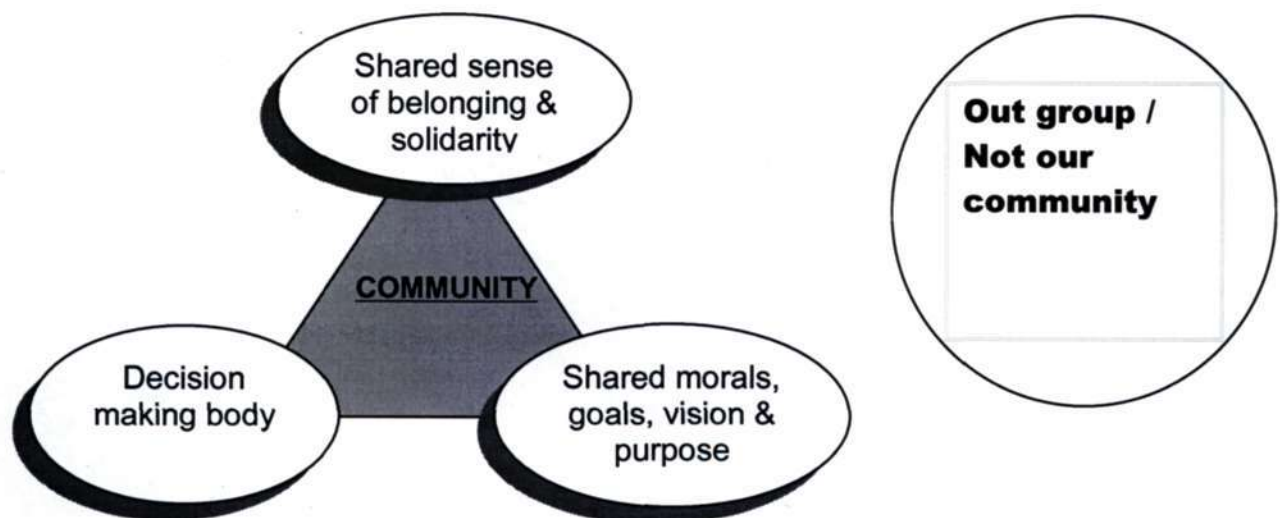
The researcher was surprised at the lack of knowledge about HIV/AIDS. In a country that has embarked on numerous information dissemination programmes, it seemed astounding that many individuals either did not trust or did not understand the information that had been made available to them. Seven of the nine plenary report back sessions contained mainly questions about what the real nature of HIV and AIDS, with many expressing their bewilderment by repeatedly stating that this is new to them and that they do not understand it. Most community members consider HIV to be a sexually transmitted disease, and therefore find it difficult to understand why children and good people can be suffering with this disease. HIV and AIDS is frequently referred to through the use of pseudonyms and acronyms, the most frequent seeming to be the "slimming sickness". This carries some inherent risk since anyone who appears to be losing weight, is considered to be a potential HIV sufferer.

Due to the many questions that were raised, this section of the SP became more of an information dissemination session than an opportunity for the community members to engage with their own knowledge base. It would therefore not be an accurate reflection of the process to give the details of the community conceptualisation. The researcher was struck by the similarities encountered in the focus group discussions conducted by Marcus (2002), and the concepts prevalently held in the partnering communities in this research.

9.2.5. Community:

69 people from the nine sites participated in discussions to define the term community. It was important to collectively explore the concept of community as this programme is based on people feeling a sense of community and cohesion. Until people identify themselves as a community and share a sense of mutual belonging, there is no real community (UNAIDS Technical Update, 1997, p.3). Three major components of community emerged during this process, with much similarity in the way in which these were expressed (See Figure 9.2).

Figure 9.2: Community conceptualisation of community



Community as having

- **Shared sense of belonging and solidarity** in which there was a collective consisting of an in-group and an out-group: “We belong together because we have lived all our lives together, and we will try our best for each other”; “A cluster of people who belong together, maybe because they all go to the same church or because they all have the same morals”; “We belong together and will always help each other out - like if someone has a funeral, we all make a contribution”;

“Those people who live next door, but who do not live according to our standards, are not part of our community.”

• **Shared morals, goals, vision and purpose:** “A community is united by the same values, norms, morals and ethics”; “A person becomes a member of the community if they share the same morals as the other members of the community”; “It is a group of people who are united and share the same practices. For example, on Mondays the people in [Rural C2] do not fetch firewood, do not go to the fields to do gardening, etc.”.

• **Community as a decision making body:** “Members of a community are free to voice their views when it comes to issues affecting their community”; “When something happens, we call a meeting to decide what to do”; “When there is a death, sometimes the whole community have to decide what to do with the belongings, how to reach the relatives who work in town and when to have the funeral.”

Some definitions incorporated various aspects into one sentences: “People who share the same belief, principles, or customs and who jointly take the decisions for the well-being of everybody who fall within their sphere” (Rural C1).

Unanimously, it was decided that communities are not defined on the basis of geographic region, except for traditional or political purposes. “Our Inkhosi rules this whole area and sometimes he calls us together to tell us something. Then everyone in this area becomes one community.” “Councillor X thinks this is one community just because he is in charge of Ward Y, but there are a lot of people here who do not think of themselves as having anything to do with him. We are only a community in his eyes.”

It is interesting to note that when the participants were completing the community profiles, people were requested to form small groups on the basis of membership of the same subgroups or communities. Following the instructions given, they drew maps of their communities on the basis of (i) geography: rivers, hills, roads; (ii) traditional authority demarcations; and/or (iii) political boundaries. They presented their community profiles in this manner and usually indicated where their own members lived, worked on projects and spent leisure time together. People who had defined their own in-group often came from diverse geographic areas. It seemed that participants felt strongly that a community develops when people share purpose, morals, vision and goals. Retaining membership of a community depended on adherence to these morals. Community members would speak to people who had transgressed, and then help them to again become integrated into the community’s functioning.

While one could debate the other dimensions inherent in these community-based conceptualisations, they served the purpose of the action research as they reinforced the notion that people in a community work together to achieve a common goal (Lev-Wiesel, 2003). Of concern, there was also the explicit process of deciding who belonged and who did not, so that it seemed that if vulnerable children were included as part of the in-group, the community were likely to assist them. Whereas, if they were considered to be part of an out-group, perhaps because of the behaviour of their parents, there was a danger that they could be excluded as participants of any community-based initiatives.

9.2.6. Vulnerable children and orphanhood:

As predicted from the literature on perceptions of orphans in African cultures (Giese et al., 2003), the community members defined orphans as children who have no-one to care for them, and not on the basis of parental death. A child is considered to belong to the family and not to parents, so that a child will frequently have various members of the extended family as their primary caregivers at different stages of the child's life (ibid.). The concept of a child who has no one to take care of him or her, is abandoned or neglected seemed to resonate with community conceptualisations of orphanhood connected with vulnerability.

It was interesting to note that seventeen of the children who were identified by community members and educators as not vulnerable, did not have parents taking care of them, but had either grandmothers or aunts as their primary caregivers. The definition of an orphan as being a child who has no one to take care of him/her was most apparent when administering the primary caregivers' questionnaires. The conversation would frequently run along the following lines: Research assistant: *Is this your child?* Respondent: *Yes.* Research assistant: *Did you give birth to the child?* Respondent: *No.* Research assistant: *Is this child an orphan?* Respondent: *No, this is my child.* Research assistant: *Where is the person who gave birth to the child?* Respondent: *She is dead.* Research assistant: *Where is the father?* Respondent: *He is dead/his whereabouts are unknown.* Research assistant: *How are you related to this child?* Respondent: *He is my child now.* Research assistant: *How were you related to the person who gave birth to the child?* Respondent: *The mother was my child/sister/cousin/husband's first wife, etc.*

With the guidance of the facilitators, all communities arrived at operational definitions of vulnerable children as those children who were experiencing especially difficult life circumstances. The factors that were considered to expose children to adversity were similar across all regions, and included (i) death of family members with whom the child had close relationships; (ii) home-based care of a dying person with whom the child has a close bond; (iii)

extreme poverty with no food security; (iv) child sexual abuse, especially rape; (v) neglect due to parent living and working away from home; (vi) drunken, alcoholic, or other substance-abusing primary caregivers; (vii) being cared for by someone who does not love the child - possible reasons were given as the child having been conceived during a rape, step-parents, immature parents and sick parents; (viii) exploitation of the child to perform labour as primary caregivers either could not do tasks or were not willing due to parental laziness. For example, lazy caregivers may require a child to do excessive household cleaning, caring for the sick and other general duties were mentioned.

During the SP, participants were asked to perform psychodramas of the situations that they felt placed children at risk. These were unfortunately not video-recorded as they proved to be a powerful method of bringing home the message of the psychological distress that many individuals, especially children experience. Generating a list of psychosocial and behavioural consequences of exposure to risk factors was then an effortless task, given the empathy that had been generated during the psychodramas.

The implications of being raised without love created much sympathy. It was also useful for the researcher to realise the extreme distress that is associated with poverty. The psychodramas portrayed family members as being sick with worry, irritable, feeling completely powerlessness and starving themselves. Educators and health care workers were frequently portrayed as especially discriminatory in their behaviour towards children from poor families.

To re-iterate the purpose of developing the community-based conceptualisations were multi-fold: (i) it enabled the researcher to be sure that there was a common understanding shared between herself and the community members about these key issues; (ii) it enabled the researcher to ensure that the concepts that the community used were incorporated into the further sessions in the SP, by continually referring back to the definitions that had been developed by the community members – this served the objectives of formative evaluation and empowerment, and (iii) it desensitised community members into thinking and speaking about the critical issues, even though there was a cultural taboo against speaking of or dwelling on some of these issues.

9.3. Summative evaluation of the effectiveness of the SP:

The SP was evaluated using multiple methods: (i) the post workshop evaluation questionnaires were completed by all SP participants; (ii) focus group discussions conducted by an independent researcher with representatives from the nine partnering communities; and (iii) community initiatives that were started as a result of people having participated in the SP.

9.3.1. Post workshop evaluation questionnaires

The post workshop evaluation questionnaires were distributed during the penultimate session of the SP. The questions proved to lack specificity in that various respondents gave responses that indicated that they had not fully grasped the meaning of a specific question, however there was very little repetition within individual's set of responses. However, across subjects similar responses were provided for questions 1, 2, 3, and 6 (See Appendix H). All of these questions tapped aspects that the participants had found useful. Questions 4 and 5 asked for information on what had not been useful or inadequately covered, but positive support for the course was frequently again provided at this point (e.g. *"Nothing, everything on the course was useful in my work with children and my community"*). Therefore, the responses to different questions were not separated for the thematic analysis. The level of sophistication in terms of the methodology does not warrant as much detail in the analysis as the focus group discussions.

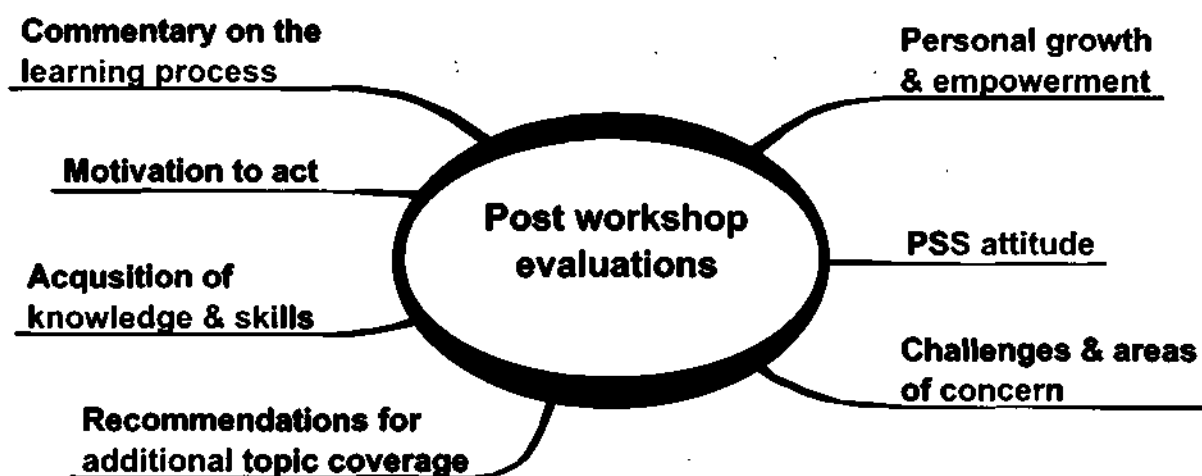
The feedback from the 254 participants was full and rich with the overall evaluation being extremely positive. Nearly all participants reported that the course had been highly relevant to their lives and that they felt empowered by the knowledge and skills gained during the course. Six interdependent content areas emerged reflecting the value of the SP, with much overlap between these areas: (i) commentary on the learning process (ii) PSS attitude, including the relationship with the facilitator, (iii) personal growth and empowerment, (iv) acquisition of knowledge and skills, (v) motivation to act, and (vi) recommendations for additional topic coverage and for other sectors of the community to participate in the course (See Figure 9.3 and Appendix N).

Commentary on the learning process: The process of training was experienced as extremely useful. Respondents found the manner in which the course was run was empowering, encouraged participation and enabled people to realise their existing knowledge base. Many contrasted this with previous courses, in which they had been cast as 'ignorant people' who knew little at the commencement of a course. Reflecting on one's own life experiences was reported to be an especially useful and empowering technique. For example, 63% of the respondents reported that it was useful to remember their own experiences as children and of death, to help them to understand how others would feel. Thus, the participatory and experiential process of learning was extremely useful. This result is consistent with the adult education literature that emphasises the need to acknowledge life experience and prior knowledge.

Personal growth and empowerment: Closely aligned to the preceding area, many responses reflect personal growth and empowerment, as opposed to reflections on the process of learning. 58% of the respondents used the term 'empowered' to describe the value of the course to them personally. This was a significant response since empowerment was not an explicit focus area, and as far as could be recollected, the term 'empowered' was not used by the facilitators during the SP. Beyond the explicit description of the course as empowering, the other most frequently reported aspects of the empowerment theme (in rank order) were increased self confidence, greater awareness of own knowledge and skills, proud of what they had achieved during the course, discovering (and having recognised) pre-existing knowledge, and the usefulness of participating and interacting with others so that a feeling of shared responsibility was fostered.

It seemed that empowerment occurred at two levels: (i) at the individual level respondents felt affirmed and recognised; and (ii) at the community level a sense of cohesion had been generated. Many (72%) reported that it was especially useful to work in small groups as this provided an opportunity for participation. Respondents felt proud that they were able to stand in front of others to give the plenary feedbacks and be applauded for their efforts. It was probably women who were more likely to comment on their surprise at speaking in front of others, but as the evaluations were anonymous there is no way of checking the validity of this assumption.

Figure 9.3: Aspects of the effectiveness of the SP based on the post workshop evaluations:



PSS Attitude: 87% (n=221) of the respondents reported that they felt affirmed by the facilitators who had demonstrated PSS by being loving, concerned, respectful and friendly. The experience of the SP had helped them to know the value of showing love and care to children as well as to their own family members. Many (78%) expressed gratitude that someone had cared enough to

train them and realised that they now needed to care enough to help someone else. Respondents frequently (84%) reported that they had previously felt powerless and helpless when confronted with vulnerable children. They had seen the plight of many children but felt that they could do little to help. Their overwhelming feelings had been of hopelessness, knowing that they need to meet their own basic survival needs and were thus limited in their ability to provide food, clothing and other material items. Realising that children need PSS, and that they had the love, time and energy to give to vulnerable children, had been a tremendous relief for many. Participants reported growth in self-confidence and direction to know that offering PSS was within their ability. 76% of respondents found it beneficial to recognise that children have feelings and beliefs, and to realise that an initial step in reaching out to children was to listen to them.

83% (n=211) commented on the value of a code of confidentiality and ethics. It seems that gossip is a problem that many encounter regularly and so fear it.

Acquisition of knowledge and skills: Respondents reported that they had acquired knowledge and skills that they would apply when working with vulnerable children. Although some of the components of this theme appear to duplicate the themes mentioned above, they are presented as part of this theme, if the respondent reported it as newly acquired knowledge/skill applicable to working with vulnerable children, as opposed to being of personal value. Most respondents reported that they had learnt how important it was (i) to be kind and friendly towards children, (ii) to show them respect, and (iii) to try to understand how children felt. In total, these three aspects of discovering how to relate to children were mentioned 734 times in the evaluation questionnaires, with 235 (92,5%) respondents reporting all three aspects. This reporting is partly a result of prolonged discussions and extensive debates having taken place about the attitude that one adopts in dealing with children. During the SP, many had argued that it was a cultural tradition to be firm and expect children to show respect and obedience. Many recalled their own childhood experience of feeling excluded from major events in the family. PSS is primarily about adopting a caring and responsive attitude, and so perhaps this resoundingly positive response reflected the primary focus of the course.

Basic counselling skills were the next most valued aspect of new learning, with 84% including this in their responses. Some respondents identified active listening (n=126, 49.6%) and understanding feelings (n=87, 34.25%) as helpful processes in offering basic counselling. It seemed that many realised the importance of bolstering coping and developing self-esteem by helping children and adults to express their feelings. 65% reported that it was useful to know

how to develop resilience, with 57% stating that they had found the resilience building technique (I am ..., I can ..., I have ...) from the International Resilience Project (Grotberg, 1999) especially relevant. Many had started to use this technique themselves and/or with their own children. Bereavement support had been considered to be useful by 34.25% of respondents and many commented on the utility of this model for adults and children. 23% commented that the same model could be used to assist abused children.

The SP was reported as creating a sense of community cohesion for 82.2% (n=209) of the respondents as they felt that they now knew and understood each other better than before. The inclusion of the community profile activity had been motivated by the need for the facilitator to understand the community contexts. It was therefore surprising to find that during daily evaluations and on the post workshop questionnaire, the completing of community profiles was reported as being beneficial for 73% (n=186) of the participants. Respondents found it useful to think about their community along the provided dimensions (Killian et al., 2002). Although the majority of respondents had lived in their communities all of their lives, they found the task of considering their community from a holistic perspective novel, enlightening and encouraging. It seemed that the task enabled participants to feel less overwhelmed by their problems and lack of resources. With increased understanding, they felt better able to accept their own historical and cultural context.

Motivation to act: Most (n=208, 82%) were motivated to apply what they had learnt to offer PSS to vulnerable children and within their own families. They reported that with their increased confidence and a greater sense of cohesion as a community, they felt positive about what they had to offer and what they could collectively achieve. The level of reported motivation, enthusiasm and commitment was high. However, this may simply have reflected the immediate response to an enjoyable and motivating course. Few respondents seemed to have considered their time constraints, the impact of volunteering on their own income and employment prospects, nor the longer term implications of this type of emotionally intensive work on their own lives. Commitment towards sustained effort may prove to be difficult.

Challenges and areas of concern: Certain aspects of the course require consideration. 11% (n=28) of the respondents reported that the course material had been overwhelming and they had lain awake at night thinking about the material, their own negative life experiences and the stressors in their lives and in the life of their community. Twelve (4.7%) people reported finding it extremely difficult to arrange for someone else to shoulder their responsibilities while they attended the five days of the course, even though they all stated that they would attend again if

the course was offered. It is important for facilitators to be sensitive to the pressures and stress that many individuals experience on a daily basis.

Recommendations: Some useful recommendations were made in terms of additional topic coverage and for offering the SP to other people. The SP needs to incorporate more information on (i) HIV/AIDS as although this is not explicitly covered in the SP, the information that was given was positively received as coming from a credible source; (ii) how to access birth, life and death registrations and social grants, and community rights in this regard; (iii) a greater focus on the impact of child abuse and neglect as this is highly prevalent and many questions arose about the victims of abuse, especially in the follow-up support meetings; (iv) more information on appropriate discipline techniques, especially the value of positive reinforcement; and (v) discussion on the impact of children taking primary responsibility for the care of elderly and sick family members - it seemed that many children do much of the HBC of dying parents and relatives.

Educators, clinic staff and leaders (political and traditional) were identified as individuals who would benefit from participating in the SP.

In general, it seems that on the basis of the post workshop evaluations, the SP served its purpose of sensitising community members to the psychosocial needs of vulnerable children and generating motivation to take action on behalf of the children. Some important challenges for the participants were brought to the attention of the researcher and recommendations made for future application of the programme for different groups of people, especially to service providers and people in leadership positions.

9.3.2. The focus group discussions:

The method used to conduct the focus groups and to translate and analyse the thematic content are set out in Chapter 9 above. The analysis of the focus group discussions will be presented according to three focal areas: (i) Effect on the participants; (ii) Effects on the community; and (iii) Comments pertaining to the course itself and about the facilitation of the course (See Figure 12.4). The full focus group transcription is to be found in Appendix K..

9.3.2.1. Effect on the participants:

The SP provoked much thought and personal engagement that was, at times, experienced as overwhelming. The course stirred up emotions for many of the participants creating existential angst and causing them to critically reflect on their own life histories and situations.

Acknowledging the relevance of the course material to their own life circumstances, created a situation in which many lay awake at night pondering over the course content, wondering about the meaning of life (and death) and thinking about how the course was changing their own cognitions, perceptions and attitudes. Despite the anxiety, the researcher believes that this was beneficial, as it seemed to enable people to see that they had a personal responsibility to bring about change.

I also used to lie awake at night and think about the children that I would see everyday, but then I would think, but I was just like that (recalling her own childhood). I have also been through all those things. But now we can change the way for the children.

The main thing was that we had to think about life and even death and this new sickness. And we had to think about children.

I felt very much relieved because then we had a way forward. ... It is good to be busy, it gives us the hope and we have to take our life like more serious.

The provocation to think was reported by many of the focus group participants who had found the reflections, thinking, planning and repetition of some of the content useful to help them memorise the information that was presented. It was also encouraging to note that many participants reported that they were pleased, and at times surprised, to realise the extent and quality of their own knowledge base.

Our community will say that we learnt to think. We used to of being busy getting on with our own lives and our worries. But this course made us to stop and think.

Yes, it is not like we learnt new things, but we learnt how to think so we could see a way forward.

It was quite refreshing to know that even if some of us do not have too good an education, we knew the answers, and then we could discuss it and see that we knew as much as [facilitator] about children.

The course enhanced coping by drawing people together to face adversity and to realise that many people share the same difficulties. It seems to have broken down the sense of emotional alienation that was pervasive among the participants. Many of the participants had kept their emotional pain and grieving to themselves and had experienced relief once they had been able to share this with others.

So even though it was serious, it was also fun but then it brought up some painful memories. [...] Well remembering seemed better, It was as we talk about the things that we had never spoken about, we knew it would be fine and then what I can say is that we felt relieved.

I felt better. My daughter and my son died from AIDS, but I have never spoken about it, because I am the Mother, and then we had to speak about it [During the SP]. And I felt very much relieved. [...] I can that is for me too.

The SP enabled the participants to feel that there was a way for them to respond psychosocially and with limited financial resources. It seems that in some particularly difficult situations, people had co-operated with one another to form a united community group who could trust one another

and set a good example for others. Being regarded as trustworthy in turn generated a sense of self-pride.

It is the psychosocial support. That we can do things that are kind and caring and it does not cost the money.

We know that we are to be trusted and this is new to us. [...] So, having someone.... Who? ... trust you, makes you feel good. Who gives you trust? [...] Like first it was just [facilitator], and then we got to trust each other and now the community trust us. [...] We knew that we were doing a very much trustworthy job and so we had to live up to the trust.

Many of the focus group participants commented that they had grown in self-respect and confidence and consequently playing an active role with their community.

I never knew that we could do such a thing, and then we did it and that made us to grow in confidence and see that there is hope for us. [...] When we had to stand up and say, we would feel proud. But I also felt proud when I heard what our group had reported and discussed and it made me to think that we knew quite a very lot.

We just thought that if we are kind and do things well, then we will feel proud of ourselves and our community.

One of the outcomes of the course was that it gave people focus and activity so that they felt that their lives were now busy, fully occupied and some had even had to develop strategies to assist them with their already overburdened lives. While in general it seemed that for women the additional workload was stressful, men in particular seemed to appreciate the extra occupation that broke the tedium of the life of the unemployed.

But sometimes I think that I have no time to do my housework and washing. Then I say to myself, that the housework can wait, or when [name of another community volunteer] comes, they will help me quickly do the cleaning and fetching the water.

Like in the past we were all unemployed, and now we are busy. [...] We are the volunteers, but being so busy makes us to feel better. [...] It is like each day something has to be organised. So now there is no spare time.

Well actually what I can say it that it helps us both. We wake up and think we have to do this and that, and we can't sit and think about our life. We have to get the things ready and have planning meetings, and then arrange with the families. This keeps us very much busy.

Now I have to wake up and go to meetings. I have had not work from the time that I have left school. Now this job does not pay, but I have to do many many things. Now I think I can't just hang around and be cool, my brother, I have to get the things ready, and write the records and all those many many things.

While in the post workshop evaluations, one of the major foci was on the acquisition of skills and knowledge, during the focus group discussions, it seemed that the change in lifestyle and their improved status within the community was a more prominent outcome. Three major areas of skill acquisition were mentioned: PSS, counselling skills and organisational skills. Repetition of course content and numbering of concepts served as useful memory cues.

What is PSS? [...] Psychosocial support. [...] There are three parts: we have to think about the feelings, that is new to us. Then the number two is the social that we have to make communities to grow again and make the vulnerable children feel loved by the community and the volunteers...[...]

And make them feel like they belong...[...] And then the support part is where we tell the children that we can listen... [...] With our ears, eyes, hearts and heads (laughter as everyone mimics the actions of the facilitators).

... it was the rules about how to make the children able to cope up with their problems. Like someone must give them the praise when they have done something that is good, and we need to make them feel that they belong with our community and we care about what happens to them. [...] And that they have a right to express their feelings in a nice way. [...] Yes, they can talk about their anger, but they must not beat up the other one, because then they would have no friends ... [...] All of us, not just the vulnerable children need the friends.

It's like we listen with our ears, but we have to watch the child to see what the face and body and feet are saying. ... [...] And we have to think about how we would feel and then we have to have this empathy.

We have to love the children and listen to them. [...] And think, what do they need, not for basic needs but in their hearts and minds. [...] Emotionally, socially and spiritually. [...] When we give children PSS, then they are able to cope up with the bad things. This was a new thing for us.

[Empathy] Its like when we have to think how the child is feeling and then we have to tell the child and let the child tell us if we get it wrong. [...] It is to help the child to know how she is feeling. And then we can understand the kid and then the child will feel empowered about what the problem is.

It was like the what what with the child, and then those five parts for educational and what what [...] Educational, emotional, [...] Spiritual that prayer and knowing our culture and teaching the children [...] And what was the other? [...] The basic needs like security, and those things that took the money [...] Education is another one that took the money.

[Rules] Like we have to work in groups, and get the permission from the parents...[...] And keep the records. [...] Yes, that we are very much useful to our community.

Being able to identify vulnerable children, plus the communities' subsequent decision to conduct door-to-door surveys to collate registers of vulnerable children had been useful in bringing home the severity and the extent of the problem. This in turn inspired them to formulate and implement further initiatives to assist the vulnerable children in their areas.

We learnt a lot about vulnerable children and abused children.

The other thing that was very much useful was to make a door to door research and find the vulnerable children and then to make the list into a register. [...] You did door to door visits ... [...] We had the three people to go from house to house and find out the circumstances and then if there were any vulnerable children, we could offer our services and tell them the plans of action. [...] We did that too. [...] We also had to do that, but it was very hot and it was hard to do, but now we know ... [...] And we took it back to the community development forum, so they could organise the gardens and the community HBC.

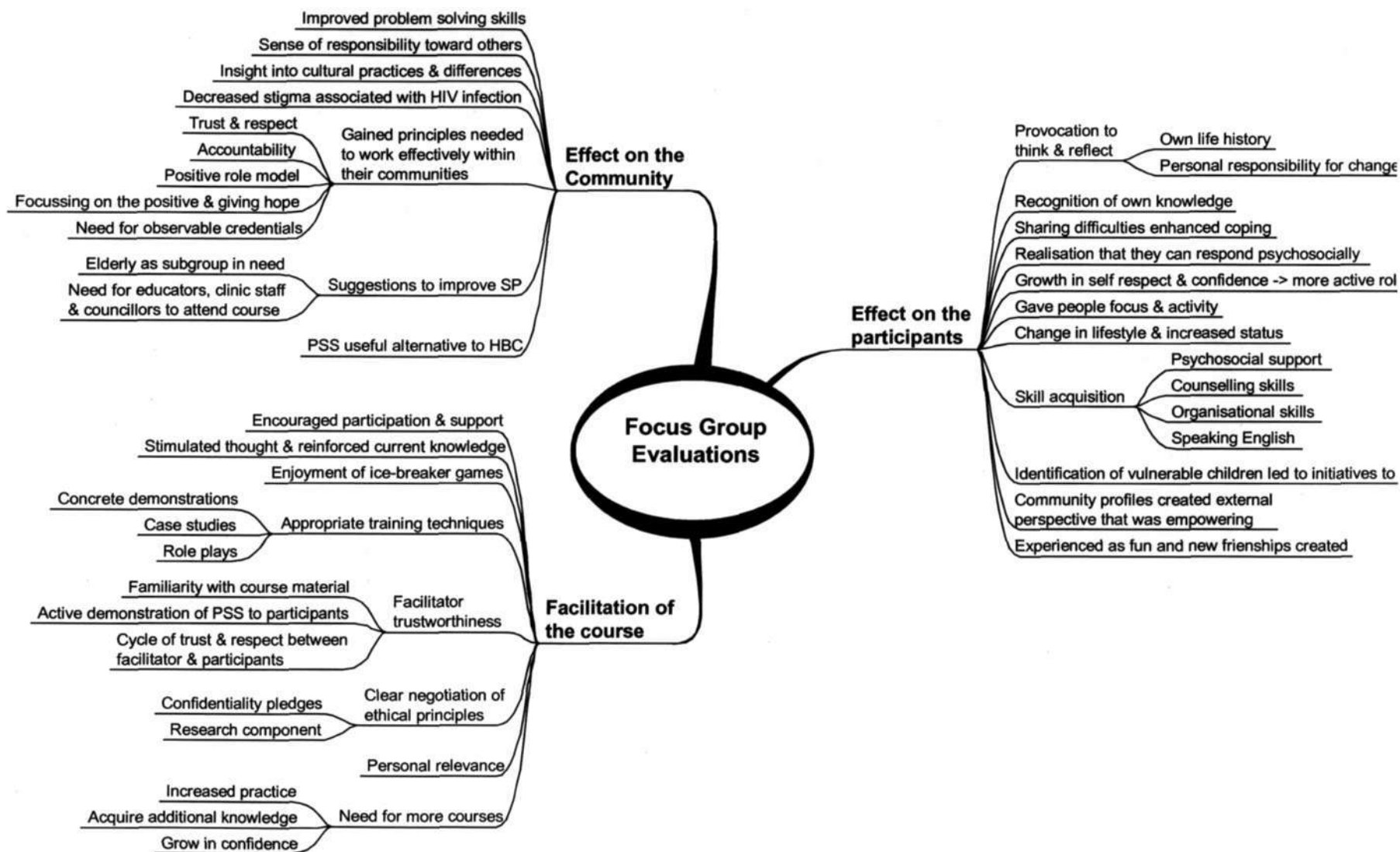
In the same manner, it seemed that talking about their communities while completing the community profiles enabled a process of externalisation that was empowering in that it enabled participants to see a way forward.

No mine was different, what we learnt about the community and what we had [...] And not just what we did not have. That is true we learnt to focus on the positive in our community and in ourselves and in the kids.

She said we had to tell her about our community. And most of us have lived here all our lives, so we thought it was an easy assignment. But then we found it too hard. It was enlightening to think about

our community and answer the questions. [...] No, we thought we knew all this and that. But then we had to tell what the history was and no-one tells us about the past, we just hear here and there about the violence. And to this day I do not know what the violence was, ... We discovered many things about our community on that day.

Figure 9.4: Effectiveness of the SP based on the focus group discussions



It was heartening to know that even though the course had created existential angst for some of the participants, it was also experienced as being fun with much shared laughter and the creation of new friendships.

Well actually what I can say is that it was lots of fun. We laughed a lot. One of my brothers had a pain from laughing so much, but it was also sad.

You mean you have made new friends [...] It is like we are now part of the same vulnerable children family.

So even though it was serious, it was also fun but then it brought up some painful memories. [...] Well remembering seemed better, It was as we talked about the things that we had never spoken about, we knew it would be fine and then what I can say is that we felt relieved.

Several participants also viewed the course as an opportunity to improve their English language skills - skills considered to make them more likely to acquire employment.

We all learnt more English and we need English to be able to get a job.

Despite the existential anguish, there were clear benefits for the individual participants, the most outstanding of which were growth in self-confidence, pride and a sense of purpose.

9.3.2.2. Effect on the community:

Although it is difficult to differentiate between those factors that were helpful to individuals as opposed to the community, there are various aspects that seemed to primarily benefit the community. Participants reported having (i) improved their problem solving skills, (ii) gained a sense of responsibility towards others, (iii) gained insight into cultural practices and differences, (iv) decreased stigma associated with HIV infection, and (v) the principles needed to work effectively within their communities. They felt motivated to engage in various activities that will be presented later in this chapter (See 9.3.3), even though they were raised in the focus groups discussions.

With respect to problem solving skills and taking responsibility within the community, listening, thinking, planning and organising were identified as critical components of problem solving.

Having older and younger participants on the same SP enabled the generation gap to be bridged so that people realised that each had something to offer the other. The growth in self-esteem and status of the younger participants was especially useful.

Like we thought that the ideas of the older people were different [...] and then we could make friends with young and older generation [...] and we got to work together and understand each other. [...] Yes, it seemed that working together with different ages, helped people to work together.

If we, as youth want to do things the old ways, then we have to go to the old people to find out, as usually and normally, actually our parents do not know. Like we just got told to do this and that, and

so on. And we just did it, but now we begin to think, why did we do it, and we can now go and ask why, so that we will know.

When we began, I thought we were going to have a problem with all these youths who know nothing. I do not mean to offend you, but actually I thought ... you know nothing about children. Then when we worked in small groups, I was so surprised, because like the one girl, who we thought was like stupid about children, knew a lot and she even by the last day stood to give the feedback in front of everyone. I nearly cried when I saw how much she had learnt and coped.

Rethinking of certain practices that had been perceived to have cultural origins was deemed to be useful. In particular, considering children's feelings and talking to them about death was experienced as unfamiliar, but had the potential to be helpful.

Sometimes it seems strange to talk to children about death at the funerals as this is not our way, but I can see that it is very much helpful. [...] That is true, and to talk to children about their feelings is different, it is not the way of our people.

In our nation, we would know that there are children, but it is new for us to think about them and their feelings. I can say that we are not used to that, with the way we have been brought up. ... Well that is to say, that in our nation, we do not really think about how children feel. We just say, agh, children are children. Now we had to think about how the children feel.

No, we thought we knew all this and that. But then we had to tell what the history was and no one tells us about the past, we just hear here and there about the violence. And to this day I do not know what the violence was ... We discovered many things about our community and our culture on that day.

Provoking people to think about situations enabled some to overcome prejudice against HIV/AIDS affected individuals. The stigma associated with "bad deaths" seemed to also have been reconsidered with some decrease in discrimination.

Helped us to think that maybe some of the people who have HIV and AIDS are not too immoral.

Like she explained how we must not share razors and toothbrushes, and sometimes it is not your fault if you get AIDS. [...] Like she said good people can also get the HIV and AIDS. [...] That was something that was different. We hear the mother-to-child stuff, and then we see a child who is dying and that child she is only twelve years old. So then we think that she was like a prostitute, but now [facilitator] said maybe another reason why she got AIDS.

Like if someone was a bad person, then they must have a different funeral. But with this AIDS, we don't know what to do. So sometimes we say that the person died of TB or asthma so we can give them a good funeral and let them go in peace. Now we know that even if it was AIDS, then maybe they were also good people, not immoral like criminals and prostitutes.

What I can say is that it is useful to say to people that good people can also get AIDS, and then there is less stigma. [...] Stigma is very much a problem.

That you can't catch AIDS from breathing the same air, and there is no danger to those who want to volunteer. [...] That good and bad people get AIDS. [...] It is not the fault of the children.

Participants had felt trust and respect had been demonstrated and were the prerequisites for effective community work. The formality of signing pledges of confidentiality, and the perceived special care taken of the signed pledges by the facilitators, were considered important elements

that would counteract a tendency to gossip and to facilitate the development of trust. Furthermore people became aware of the fact that to be trusted, one needed to be trustworthy.

It helped us to know that we could say that we signed the pledge. [...] That pledge was something new to us, but it was very much useful. ... I think the rules were also useful; [...] Which rules? [...] The one about right to be private and not to gossip and to be caring and non-judgmental.

Yes, I was always scared of what people would say, but I would also like to gossip (laughter and lots of agreement) and then we had to sign this form and there had to be a witness, and this was something new to us.

In our nation, gossip can be a very big problem. We like to know what is going on. So after we signed the pledge of confidentiality, then it became a serious matter and we knew we had to keep this.

But like we don't like to talk about the bad things. In actual fact, I learnt that we do not talk much about things but each other. But then on this course, we actually came to realise that it is not good to be talking about that someone ... and that we must stop this, and keep confidentiality and be trustworthy.

We know that we are to be trusted and this is new to us. ... So, having someone trust you, makes you feel good.... Like first it was just [facilitator], and then we got to trust each other and now the community trust us. [...] We knew that we were doing a very much trustworthy job and so we had to live up to the trust.

Like we have to be a good example for everyone. [...] It's like from being no-one, we have to be trustworthy.

Being accountable to others, a positive role model, focusing on the positive, and giving faith and hope were considered to be essential elements of being accepted and effective within their communities.

It means that we have to be a good example, and not drink or smoke dagga, or fight or beat our girlfriends. [...] We have to set a good example, so people will have the hope in us.

And to take action, it is our future that we are playing with here. [...] It is our responsibility [...] That is right, because the course won't help the children, we must do that.

I think what was good is that it showed us to have faith in us and to know that we can have the direction to go forward with the vulnerable children.

We knew that the children were growing to trust us and so we could not let them down. [...] Now when I walk in my area, then I know that the children must be watching me, so I have to be like a VIP,.... No, what I mean is that I have to always be the kind and trusting person, otherwise people won't trust me.

Like everyone has even the tiniest thing in them that can give them hope and we just have to find that little thing like a seed to make it grow.

Some very useful suggestions were made about how to improve the course or to increase the outcome and impact of the course. Some of these suggestions arose because community members had encountered certain difficulties, whereas others recommended additional focus areas or offering the SP to other subgroups of people.

Several participants reported that they had experienced some difficulties in gaining access and/or being accepted and they requested that they be given observable credentials that would identify them as trained volunteers.

But we need to have badges or something so people will take us more seriously.

Yes, especially the young people, the community says who are you and what do you want to do with our children. If they had badges, this would not be happening.

The focus group participants from one of the communities were particularly concerned about the fact that they had not yet received certificates that they could show to people to prove that they had received special training and were volunteering on behalf of the community at large.

The elderly were identified as a community subgroup in special need of assistance in dealing with the difficulties encountered through vulnerable children. Some communities had already begun their own initiatives to reward the elderly for their contribution towards the well-being of vulnerable children (see 9.3.3).

... It is the old people who look after the orphans and often of the workers, so we do use the PSS for the elderly.

But I also think we need to speak about elder abuse, because now when we go to the houses, we see that everyone says what what to the gogo's and then the gogos' pension has to pay for everything. [...] The old people, they have to cope up with everything...[...] Like when someone gets sick, it is the children and the old people who have to cope up with them.

Identifying the range of adversity faced by vulnerable children enabled greater empathy and motivation to take some responsibility. The psychodramas had been particularly impactful in bringing insight to the participants about the emotional and social impact of the various adversities.

Well we said that children have many, many bad things that happen to them and we need to help them whether it is a death or this sexual abuse thing, or drunken parents, [...] Or any of the bad things, like dying and sick family members. [...] Or being teased and bullied. [...] Or mixing with bad company [...] Or seeing spooks (laughter) [...] Or no food in the house because the parents, they are not working.

[A vulnerable child] is a kid that is having a hard time and has to cope up with many things. [...] Like abuse and AIDS and sickness and deaths [...] And no work [...] And parents fighting.

But [the Psychodramas] were true, then we were inspired to do something.

The focus group participants also suggested that educators, clinic staff and councillors would benefit from participating in the SP, especially since they were perceived to discriminate against vulnerable children.

Yes, what I can say is the teachers are the worst with stigma. [...] They come and they don't want to touch the children or their books, in case they are from an infected home. [...] Some teachers are afraid of becoming infected. [...] I think most of them are.

I think all the teachers need this course so much [...] They are so smart but they don't care about the kids [...] Well actually, I think they are too busy to worry about the children.... They are always so busy with their smartness, that they don't worry about the kids, only themselves.

No now seriously enough, I think that all the people who our children have to see should cope up with this course. [...] Like the clinic people and the councilors (Laughter).

There was general recognition that the rural areas are the hardest hit, both in terms of the additional burden that the HIV pandemic has placed on them as well their lack of resources. Unwittingly the facilitator had also debunked a myth associated with HIV/AIDS.

We did not understand the water at first, then we could see that we could trust the water. [...] What do you mean? [...] You know in the rural area, some of the people say that the whites are infecting the water, so then when [facilitator] brought the water this reminded us of this ... suspicion. But then we saw that we could trust [facilitator] and she could talk about this.

... But we still have to wait, especially us who are in the rural areas. No one came to us. It was just [facilitators] who came to help us. But many of the children are sent to the rural areas to be looked after.

When there is no work, or when people are sick, they come to the rural area,... they come to us that are in the rural area and then we have nothing, but we have more of a problem. ... When someone can't keep up with the life in the town, then we send them to the farms.

Some participants considered that being able to offer PSS was a useful alternative for those who were not suited to offering HBC. Others recognised that not everyone is suited to working with children. It seems that community members who wish to volunteer their services need to have access and skills in a range of activities so that they can engage in an activity that is satisfying and offers them a sense of self-fulfillment.

I thought it was HBC, but then this was very much useful. [...] I also did not attend those meetings [CMM's], and then I thought because it was AIDS it was about condoms or HBC, so I was very much surprised. [...] But HBC makes me want to ... it makes me to feel sick. I can't do that. (Long pause) [...] For 25 years I was a matron, but I also feel sick with this AIDS thing. [...] The people get to smell and then you don't want to touch them.

But actually I find that not everyone can be nice to the children. Some are so rigid in their ways that they just tell the children what what and then they do not listen.

Like the soccer I will keep doing it 'cos then I have fun ... To have fun and to teach the children how to have fun again and join in the games.

Like we go and we do these things with the children and then we see them smiling and laughing and we feel good inside.

9.3.2.3. Facilitation of the course:

The focus group participants reported that the general teaching method had been useful as it encouraged participation and involvement, stimulated thought, challenged people to speak in

front of others, and reinforced their current knowledge.

Other courses you have to make the notes and listen. .. Most of the time it is boring to us. [...] I think because other courses tell us the things, then it does not make us to think. And we sit on our backsides and wait for the tea and the lunch. [...] But what made this course different? [...] It was because we did all the work and then we could only look at the manual at night.

This course was very different. You can't compare. Because we had to do all the thinking and the working and not much of listening. ... we had to talk to each other about the things that we think and believe.

I never knew that we could do such a thing, and then we did it and that made us to grow in confidence and see that there is hope for us. [...] When we had to stand up and say, we would feel proud. But I also felt proud when I heard what our group had reported and discussed and it made me to think that we knew quite a very lot.

What I liked the most was when we spoke in groups and we had to then stand up and report. Because, at first we did not know that we could such a thing. But then we all took turns and it was the first time for us.

After [facilitator] had left, then some of us, she and she and.... would stay and write it all down, because it was very impressive. [...] You felt impressed by what your group had said. [...] Yes, we felt proud/good/happy/trustworthy.

... I felt proud that together we had said these things. And I could see that [facilitator] was very much pleased with what we said. ... But if I had to work on my own, I do not think I would have passed. [...] It was like we were discovering that when we work together, we can know more. I think that was why she strategised us in that particular way.

Integrating new games as ice-breakers and to energise the participants had been fun. Participants enjoyed trying to pre-empt the facilitators in defining the message behind the various new games.

Well actually when we had had fun, then we would sit down and there would be a lesson and then we could see the lesson, but when we played the games, it was just fun. But then as the days went on, we would think what will the game be showing us and sometimes we would get it right.

And then we had to lead a blind[folded] person around and see if we can be trustworthy. [...] We enjoyed that game. We had very much fun. So when we discovered the lesson, we felt bad because some of us had played tricks on the blind person. [...] What happened? [...] We learnt that you have to help someone in a kind way and if you can not be trusted then you must not try to help. You must just go away. [...] ... So we saw how people feel when they have to ask for help and it is not nice.

Using concrete demonstrations, case studies and role plays were appropriate training techniques as they readily stuck in the minds of the participants.

Yes, she showed us this elastic and said that we must make children like elastic, but not sticks and grass. [...] She never said that with us. [...] She showed us elastic and said we must help children to cope up with the bad things that happen to them. [...] Yes, that is what I meant, sticks and grass break and we do not want the children to break, we want them to be like elastic. [...] Yes, then she said that with us. [...] Do you think that you can make people to cope better with the bad things that happen to them. [...] Yes, this was the PSS thing, that we need to give children love, time and energy to help them to cope with bad things.

While the participants found it useful to refer to their own manuals after the course, the fact that the facilitators had spoken without referring to a manual had been perceived as an indication that

greater trust could be placed in the material.

You must see our manuals, they are more paged than my Bible.

Actually what I can say is that she explained it very nice to us and so we could trust her. [...] I think that is serious. Because we do not know what this new sickness is, and she explained it to us, with no books. ... Yes, when we go on the AIDS course then the facilitators read from the books and then we think they do not know, and are just feeding us the propaganda.

The method of training delivery had enhanced the faith in the course content. Several participants reported that the concept of PSS had been demonstrated through the way in which the training had taken place.

I think that it was useful that [facilitator] said the same thing what she done. [...] What do you mean? [...] Like she did not say do PSS and be not kind to us. [...] It was like she was showing us the PSS, with the way that she treated us.

That was very useful. It also showed that [facilitator] believed in us and wanted to know about us. Not just tell us what we have to do.

In turn, this created a cycle of trust and respect. It became clear that the participants were hypersensitive to the facilitator's reactions and were eager to please her since she had shown them care, concern and kindness. The simple act of someone external to a community coming to listen to the participants was identified as a novel experience for community members.

Well I can just say that it was a new thing for us, because when she first came, she just listened. And it was a new thing for us, because she would listen to our problems and then she would ask about the children.

And we wanted to please [facilitator], as she seemed to believe that we could do it and she had taken the trouble to come to us in the rural area.

We thought we had to do this and that for our next meeting, as [facilitator] would come and smile and have like faith in us and we had to live up to this... Did you feel pressure to please her? [...] In a way yes, we did feel it. But we also had a way forward and that helped us to work out what we had to do, 'cos she never said what we had to do ... she made us to think and then said you can do it. [...] But she liked our ideas and we knew we could phone her if there was a problem.

The other thing is that [facilitator] very much likes our culture and wants us to do things that way. She always wants to learn about our nation and our way of doing things.

It also became clear that the participants felt affection, trust, and respect for the facilitators to whom they felt accountable.

... she was smiling and joking with us and helping us. But when we spoke the ground rules, she never smiled, but spoke serious. [...] And she put the pledges in a file. [...] With us she put them in her car every day, so we could see that she was very much serious.

... we wanted to show her the photos as the proof of what we were doing. [...] And she liked to see our records so we had to do the records.

There was evidence that the ethical principles had been clearly negotiated both in terms of their application within the communities (especially in terms of the pledges of confidentiality) and in

terms of the research component. Participants conveyed their understanding that the research was a means of establishing an effective modality of intervention and that the researcher/facilitator was hoping to be awarded a degree for the work she had undertaken. Nevertheless, it is extremely difficult and insensitive to ask for volunteers from extremely impoverished communities to offer their services for no financial reward.

She wanted to see what works best with the little of money that is available.

Actually she wanted to see what would happen when we were empowered to think about the children.

The research was for us to find out what we can do by ourselves

The research was also for her to get this degree and become the famous one.

Actually what I can say is that it was useful because then she got this money so she could do the work and pay for our lunches and teach us about these many things that was new for us... [...] ... it was also useful because then we found out what we can do and that we have a right in this regard 'cos we can say no. ... [...] And we can tell the children their rights.

Most of us are unemployed, but now we have the work. No money but the work.

The fact that the course was considered to be personally relevant also enhanced the way in which it was received and evaluated.

This course was especially relevant to us. [...] That is what I can say. It has been very useful because it applies to our lives. [...] I have not done many other courses, but this was very relevant to us, in our work and in our families. It gave me the confidence.

I used to think today it is that child who has no parents, but soon it will be my children that has no parents, and what will become of us and our people.

Yes, I thought more about my children and the children in my family first, and what was being said was true for even my own children.

Several participants commented on the need for more courses along similar lines so that they would get more practice, acquire additional knowledge and grow in confidence. The participants have applied the course material and felt empowered to continue volunteering with only sporadic supervision and support.

Like when we come across this rape thing, we could phone her. And we could ask her to come and give the trophies [for sporting events] and she would come.

What I can say is that it is like having the trust placed in us, make us to keep busy and then we feel good.

The other people are seeing us now and saying what what, you cannot be so confident. I want to also do that course.

Have you been able to use the information from this course? If so how? [...] Lots and lots. We have done many things, also that we like to do them so then we look forward to doing the fun things with the children. [...] It is good to be empowered to use the information in the way that we want and not to be told what we have to do.

There is no doubt that the greatest effects of the SP are evidenced in the community-based initiatives that will be discussed in following section.

9.3.3. Community initiatives to offer PSS to vulnerable children:

On the final day of the SP, participants were asked to consider if they wanted to develop plans of action to apply the knowledge gained during the course and to take action offering PSS to vulnerable children in their community. Some (two to five people in each of the SP partnering communities) elected not to remain involved or felt that what they were already doing (childcare, working in crèches, etc.) was sufficient.

Most of the plans of action appeared to be realistic, and in the cases where the participants had seemed too ambitious, the researcher commended their enthusiasm and tried to help them partition their plans into more manageable portions. A follow-up meeting was held approximately six weeks after completion of the course when participants were asked to report on progress made during the intervening period of time. Further follow-up meetings were conducted on a monthly basis as reported above in Chapter 7.

Community initiatives could not be monitored in a rigorous fashion since they were considered to be community owned and driven. When the researcher was asked to attend or help with an activity, she did so. The authentication of the activities taking place however relied on the honesty of a group of participants giving feedback or bringing their own 'evidence' of an activity having taken place.

The concept of PSS has been broadly understood by the SP participants with the result that a wide range of different activities has been initiated. The focus group discussions provided insight into both the nature of the activities as well as some of the dilemmas that have been faced and more or less successfully negotiated (See Table 9.2):

- *Like if we have soccer games, then the children will have the chance of feeling happy and playing and getting the exercise. And then they will feel better. And then we do sports with the young men and women,*
- *... we work at the traditional healer [to teach about MTCT, nutrition and about HIV prevention]*
- *... the life skills at the school,*
- *visits to the orphans and the other vulnerable children*
- *the vegetables and the chickens.*
- *Sunday school*

- **Read stories**
- *[Teach about] culture ... teach the Zulu dancing and stick fighting and the songs*
- *... and we do the modeling and the hygiene.*
- *We take the girls and we have to dress and wash and fix their nails and their skin and learn about looking nice. And everyone must do someone else's hair and we put things in the hair. [...] That is a township thing, not for us. [...] Is this PSS? [...] Because when we are doing these things, we are talking to the children and giving them things to do and to look forward to. [...] And then they can see that we love them very much [...] And then they will come and talk to us about their problems. [...] And then we listen with our ears, eyes, brains and hearts.*

Table 9.2: Overview of community-based initiatives offering PSS to vulnerable children:

Cultural and spiritual activities	PSS + death related activities	Community Development	Life skills
<ul style="list-style-type: none"> • Sunday schools • Emotional support at traditional healers • Zulu dancing + stick fighting • Traditional games + songs • Read Bible and cultural stories • Explain meanings of customs and rituals 	<ul style="list-style-type: none"> • Visit vulnerable children • Relieve children from HBC duties so that they can go and play • Speak to children about their problems • Memory boxes • Assistance at time of death • Bereavement counselling • Resilience building activities • Safe Houses 	<ul style="list-style-type: none"> • Vegetable gardens • Chicken farming • Dairy farming • Assistance with vital registration and social grants • Community surveys • Caring and supportive resource • Pensioners' Days • Training of School Governing Bodies • Discussion on discrimination and stigmatisation 	<ul style="list-style-type: none"> • Sports • Life skills in the schools • Gender sensitivity training • Sexual harassment awareness • Hygiene + modeling • Homework support • HIV/AIDS awareness programmes • Role models for HIV- children.

- *And the children, they like it too much. They come every time, and they bring their friends and this is something that is new for us.*
- *... the life skills and we made the boys to pretend like they were girls and we made the girls to pretend that they were the boys and we made them all to watch. And we got them to talk about this sexual harassment thing.*
- *And we can show them about how to get grants, with that affidavit and to help them to go to town to apply for their certificates. ... We were given books, so that we do not feel ignorant and we can tell the social workers which grants we can have.*
- *The SGB (School Governing Body) called a meeting, and we spoke about how to get certificates and grants and to make memory boxes for everyone, not just those ones that have HIV or TB or asthma.*
- *Then we had a party for the pensioners, so when they came to town, we had a nice cup of tea and some cake for them and they could sit while we kept their place in the queue and they very much liked that. [...] We did it now for two of those pension days and we can keep it up for the old people who are looking after the vulnerable children because then they can get the rewards of looking after the children. We take care of the children, do the children-work and playing and all those things.*

- *That thing is about "I am, I can I have" 'cos this helps the child to think about the positive and you too.*
- *The door to door search [survey] was good to help us to see what was needed and where the biggest problems were - we became the researchers of the area. You felt very important doing the maps. [...] What maps? [...] We have a very big area, so we used the mapping that we were taught and we mapped where the vulnerable children live.*
- *In our situation we had to help the children to cope with the dying members of the family. Like on the course, we spoke as if there was one person dying, then we had the family where three people were dying at the same time. [...] And we had to speak to each of the children like on their own and then to the family. But at first it seemed like very hard and we felt negative about it. Then we said we must go back to the manual and see what is to be done now. [...] Then there was four of us that went and helped the children to write the letters to their dying parents, and to say goodbye and to make the memory boxes. And we could see that the children were very much relieved to have people come and help them, because like the diarrhea was constant and the children were scared, as there was too much to be done. [...] So two people looked after the late ones [those dying] and we took it in turns to be with the children. ... That must have been a hard time for you. [...] It was very very hard, but we knew we had to cope up and do our best. [...] We had to think about the children's feelings ... [...] And the people that was dying, how they felt to know they were dying and there are all these children that will have no-one [...] But then the late people knew that we could look after the children until the family would come. ... the family came. They were not so much interested in the children and the children said they wanted to stay in their house and the Inkhozi said good.*

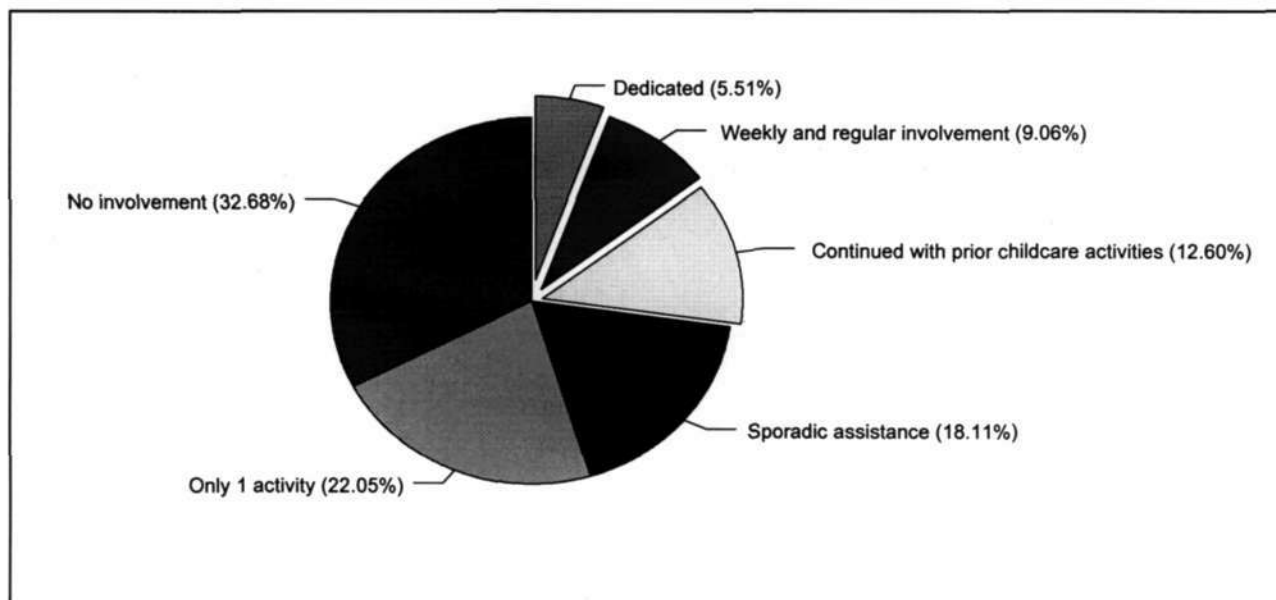
These initiatives have continued over a period of time with varying degrees of success. There is little doubt that the on-going support and interest of the facilitator is a crucial motivator. Participants at the follow-up meetings frequently reported that they had quickly organised an activity knowing that I was due to attend one of their meetings and they wanted to have something positive to report to me. The personal relationship that had developed between the researcher and the community members was critical in this regard, since if someone else was to be sent, there was less impetus to create a positive impression and a greater likelihood of excuses being given. The excuses however need to be taken seriously, since it is clear that most of the participants live stressful lives. Unless they are recognised and rewarded for their efforts, it is unlikely that they would continue volunteering.

At the time of writing-up this dissertation, the profile of commitment by the SP participants is as follows (see Figure 9.4):

- A small group of 14 (3,5%) dedicated individuals were wholly committed to offering PSS to vulnerable children, both within and beyond their own community.
- 23 (9%) people were spending approximately two hours per week in volunteering services, and an additional 46 (18%) people were engaged with PSS activities within their own community when an activity was arranged by others (defined as at least four times per year). The less engaged individuals had perhaps been buoyed along by the optimism and enthusiasm generated during the SP.

- 56 (32,7%) people participated in only one PSS initiative and then withdrew their participation. Thus as far as this project is concerned, they have been of limited benefit to their community in terms of applying their knowledge or skills.
- 32 (12,6%) people continued to work with children in activities that functioned prior to the SP (and ten of these people attended all of the follow-up support meetings). It is hoped that their participation in the SP enhanced the quality of their childcare. Some of these individuals were also willing to help with other activities, although they have not been included in the previous count of sporadic helpers.
- 83 (32,6%) people have been inactive. There is no information available as to why they withdrew their support, but a multitude of reasons are possible including finding employment, becoming ill, dying (the researcher knows three of the SP participants died of AIDS-related conditions), lack of interest, etc.

Figure 9.4: Degree of involvement by SP participants in PSS activities from data obtained at the six-month follow-up session with SP participants:



Despite the highly positive appraisal given by the SP participants in both the post workshop evaluations and in the focus group discussions, the majority of the SP participants were not inspired to sustain their efforts to offer PSS to vulnerable children. A more optimistic view shows that 45,2% became involved or were already involved. There are now an additional 37 community members (approximately 4 per community) who regularly commit time, energy, care and concern to vulnerable children. Whether this is cost-effective or not is debatable in the light of outcome measures for any training course. It is believed that the SP can be viewed as a positive step in the right directions, with perhaps a need for greater discernment between those who are likely to volunteer and those who will be inactive. The comments about the course

content being highly relevant at a personal level suggests that maybe some of the inactive individuals could have applied their skills in less public forums by improving their parenting skills or care and concern for neighbouring/family children. The international literature would support the more optimistic view, since it is recognised that volunteering incurs substantial personal costs such as time, financial resources, energy and personal commitment (Omoto & Snyder, 2002; Paolicchi, 1995). Volunteerism is a highly complex process (Ollis, 2001) in which the anticipation of personal gain accounts for some individuals participating in volunteer work despite the high personal costs (Omoto & Snyder, 2002). There are a number of studies that indicate that once individuals have received extrinsic rewards for engaging in an activity, their previous intrinsic motivation decreased leading to a detrimental impact on the quality of performance and decreased motivation to act unless extrinsically rewarded (Sansone & Harackiewicz, 2000). There is however an urgent ethical and humane need for macrosystemic intervention in the form of government policies to consider ways of supporting and rewarding the efforts of volunteers (Snyder, Omoto & Crain, 1999), alongside concerted poverty alleviation programmes.

9.4. Discussion of the results of this aspect of the research

9.4.1. Community based conceptualisations

The discussions on the meaning of various concepts enabled participants to debate and clarify their thinking on these key issues. The basic rationale for including this aspect of the research was that community members would be major conveyors of meaning, attitudes and cultural interpretation to vulnerable children within their communities. It allowed discussion to take place about the developmental niche (Super & Harkness, 1987) for children living in each of the partnering communities. This permitted greater mindfulness of the psychology of caregivers and families and the customary practices of childcare and rearing (ibid.). It also acknowledged the role of both distal and proximal zones of influence in child development (Lonner & Malpass, 1984). Therefore, encouraging SP participants to speak openly about these issues and to be afforded the opportunity to clarify their own thinking contributed to the beneficial outcome for children. It also enabled the researcher to use their conceptualisations in tailoring the subsequent SP discussions to the pre-existing concepts held by a particular community. This proved to be affirming and empowering.

The most notable aspect of the discussions was the marked consistency between the community conceptualisations and those that are offered in the literature (for example, WHO, 2003). This reflected that the communities were able to engage in these debates with much sophistication.

Community workers need to appreciate the fore-knowledge of participants who may lack accredited educational qualifications yet are mindful of the complex issues involved.

9.4.1.2. Health and illness

It was clear that community members have a bio-psycho-social systemic model of both health and illness that is consistent with the definitions proposed by the World Health Organisation (2003). They recognised that understanding, prevention and intervention need to take into account all three aspects simultaneously. It was interesting to note that being healthy carries a responsibility towards those who are less fortunate and that this was seen to be consistent with 'the African way of life' (SP participants from seven of the partnering communities). The community conceptualisations were consistent with the most cognitively mature explanations of health and illness in which people demonstrated an ability to simultaneously consider various aetiological factors and to hypothesise about cause and effect relationships from different perspectives (Bibace & Walsh, 1980; O'Dougherty & Brown, 1990). They also serve as a forum from which one could challenge the dominant social narrative of HIV/AIDS being primarily a medical problem demanding treatment. While the international community is locked into the medical model's paradigm of understanding the HIV/AIDS pandemic, then relatively little will be done to change the poverty stricken conditions in which HIV/AIDS thrives, since the focus is rather on vaccination and treatment.

The extreme poverty in which most of the participants live impacted on the manner in which they see adequate nutrition as being an absolute criterion for good health. These poverty-stricken communities also regard their lack of access to resources - lack of sanitation, hygiene and running water and a generally unsafe and bad environment – as major aetiological agents for bad health and for illness. Along similar lines, younger individuals believed that those who are unemployed and have no access to money could not be regarded as healthy as they would be adversely affected psychologically and socially, and thus limited in their ability to achieve physiological health. The older individuals, however, placed greater emphasis on the social and psychological components of health, saying that one could be dying, but if one were at peace with oneself and others, then one would still be healthy [in mind and soul]. This latter view is consistent with Erikson's (1963) psychosocial stages of development in which the elderly seek to resolve a crisis of integrity verse despair.

The lack of biological knowledge about the modes of transmission of diseases, and of HIV/AIDS in particular, adds to the discrimination against those people who are infected. If people do not know the difference between viruses and bacteria, nor the difference between infective and

contagious diseases, they would logically err on the side of caution and avoid contact with infected individuals. It seems that HIV/AIDS information dissemination programmes need to incorporate basic physiological knowledge into their messages. Without an accurate information base onto which to interpret and assimilate new information, it is probable that confusion will prevail and myths will continue to be propagated. For example, if people do not understand the composition of blood and believe that once it leaves the body, it becomes contaminated with someone else's spirit, then they are unlikely to place much trust in blood results and will not be motivated to go for VCT. It was, in fact, surprising to encounter so much misinformation and confusion in a country that has spent millions of rands on various information-dissemination campaigns.

Simultaneously, the researcher found that people were highly receptive to information. They challenged, questioned and integrated the new information with that which was already familiar to them, often asking questions several days, and sometimes even months, after the initial discussions had taken place. It seemed to the researcher that as trust was developed and her credibility was established, people were more able to question and challenge as they eagerly sought out accurate, trustworthy information. It was interesting to note that during the focus group discussions, it emerged that participants had placed greater trust in information that was given spontaneously without reference to prepared notes. They contrasted this with information dissemination sessions that they had previously attended, in which information that was read from books or notes was distrusted as being part of propaganda. It seems therefore that information is best given by people whom community members know and trust, and that the way in which the information is presented is critical in terms of its' credibility. Books, pamphlets and posters were generally viewed with some suspicion, especially by those who lacked a means of evaluating the accuracy of the information. It was only the township groups who had the means of accurately interpreting information, as they seem to have been exposed to better education in basic biology. These conclusions are consistent with both (i) Piagetian theories of cognitive development in which the cognitive processes of accommodation, assimilation and equilibration are explained; and (ii) Vygotsky's information processing theory, which contends that new information needs to be scaffolded onto an existing knowledge base if it is to be meaningful and relevant to the recipients.

9.4.1.3. Death and its associated practices:

One of the consequences of the HIV/AIDS pandemic is that death surrounds the communities. Funerals are occurring with ever increasing frequency. Freshly dug graves are to be seen in all of the partnering communities, with the rural communities having the graveyards within their

homesteads. Nevertheless, it is against the Zulu custom to speak about death as this may evoke suspicions that one may be involved in witchcraft or be wishing for menace (Marcus, 2002). It was thus important that people became more comfortable with the idea of speaking about death, the associated practices and the cultural rituals that need to be performed at the time of a death. The researcher was struck by the lack of knowledge about the reasons for performing certain rituals. This seemed to have been a result of the generation of political violence during which time many people lost familiarity with their own cultural traditions. In addition, Zulu culture is in a state of rapid transition through urbanisation and westernisation. It was not unusual for SP participants to admit that in the event of a death, they needed to seek advice from the elders so that they could be told what they had to do. In some instances, SP participants stated that they found the 'old ways' curious and out of place in the modern world.

The resilience literature suggests that these trends need to be counteracted (Mallman, 2002; Masten, 2001). Children benefit from a clear sense of their own cultural roots since this facilitates the development of a sense of pride in one's history and the history of ones' people. From a psychological perspective, many mourning rituals make allowance for the bereavement and grieving processes to occur within supportive social environments. They should therefore be encouraged as necessary for people to adapt after the death of loved ones (Christ, 2001). The 'modern way' of getting back to work and resuming full functioning as soon as possible after a death does not create the emotional and social space required for grieving.

AIDS-related deaths are fraught with confusion since there is a dichotomy made between good and bad death (Marcus, 2002). The rituals associated with good and natural deaths facilitate emotional expression by those most deeply affected and there is a sense of knowing what will happen to the deceased subsequent to the death, from both Christian and traditional/cultural perspectives. Unnatural deaths create confusion and people are asking for guidance about how unnatural deaths need to be perceived. AIDS-related deaths are generally considered to be unnatural. SP participants acknowledged that at times they created the impression that someone had died a natural death (from TB, asthma, etc) simply to allow them to proceed with funeral rites and to enable the deceased to leave this world peacefully. This however caused them much anguish. There is a need for religious leaders to be more forthright in guiding people to formulate ways of sensitively dealing with children and adults when someone dies unnaturally, including from AIDS-related conditions. African cosmology makes this especially important, given that individuals are perceived as reflections of and integral aspects of their family and people (Mkhize, 2004). People seemed to especially need reassurance that the *amadlozi* would be able to form just and fair judgements about deceased individuals.

The custom of excluding children from discussions about death and from funerals was generally recalled from the SP participants' own childhood experiences as being detrimental to them. In each of the partnering communities, SP participants recalled feeling deceived when they were told untruths about loved ones whom had died. The use of a guided imagery exercise to facilitate SP participants to recall their own experiences of the deaths of loved ones and to discuss their feelings within the contained and supportive environment provided by the group was extremely powerful. While evoking strong emotions, it enabled participants to experience intense relief when they expressed their feelings, recalled their own childhood sense of being abandoned when someone died, and enabled participants to empathise with adults and children who had experienced the loss of loved ones. It also seemed to draw the group together into a supportive and caring unit.

9.4.1.4. Community:

The most significant aspect of the definitions of community that emerged was that community is a dynamic construct in which people are either deemed to be part of a community or are excluded by virtue of their non-conformity to community ideals, attitudes and practices. The concept of community is not based on shared physical space and so the strong reliance on community-based initiatives to assist vulnerable children and other members of communities may well be misinformed. A sense of community is generated through shared values, standards and morals in which people work together to create a shared sense of belonging and solidarity. The rather romanticised notion of community as consisting of a group of caring and supportive people who would be willing to help each other, even at their own expense, was not supported by the SP participants. People qualify themselves to be considered members of a community through their actions of adhering to the standards, values and morals of the community in-group. Membership of a community is not an automatic occurrence associated with environmentally defined living space. Despite some of the romanticising of the African cosmology of communalism, people who live on the bread line, with no security that their own basic needs will be met, can ill afford to be magnanimously generous to others, whom they perceive to be different.

Community development work often incorporates various target levels (personal development, small group development and then community development in the form of group decision making and income generating activities) in recognition of the fact that without personal development in which people feel better able to cope with their own stressful lives, they are

unlikely to be positive contributors to the larger community groupings (Meintjes, 2004). The results of this study endorse this approach.

Nevertheless, it is important to acknowledge that the basic rationale for volunteering is frequently based on religious and cultural values (Gothan, 2003). Recognition of this enables one to consider rewards and affirmations that endorse the important role of these factors in motivating people. The theories of action and motivation are also useful frameworks for considering appropriate methods of recognising and rewarding volunteers who give energy, time and resources. However, this must not undermine the critical role of fair financial reward for services rendered.

9.4.1.5. Vulnerability and childhood risk

The SP participants easily engaged with the concept that risk lay primarily outside of the child and could be operationally defined to include those children who were experiencing especially difficult lives. It was important from an ethical perspective, to be extremely cautious when applying labels to children and the operational definition seemed to decrease the potential stigmatisation from labelling. This form of definition also served to elicit empathy/sympathy in that children were considered to experience difficulty through 'no fault of their own'.

One of the most emotionally powerful sections of the SP occurred when SP participants were asked to perform psychodramas of children who were experiencing hardships in life. Although in general, these psychodramas were conducted with an air of light-hearted fun, the authentic portrayals served to highlight the extremely difficult situation in which many children live. For example, the discrimination that children experience at school when they arrive hungry, in dishevelled clothes and unable to concentrate seems to be extreme. The ramifications of being raised in poverty certainly had not been clear in the researcher's own mind before the psychodramas were performed. Most communities portrayed the educators as responding in an exceedingly negative manner often drawing other children into teasing and mocking children whose clothes, for example, had not been washed with soap or ironed properly. The division between children who were non-vulnerable and those who were vulnerable seemed to be huge and detrimental to all parties.

In general, the discussions on community conceptualisations served their purpose of enabling people to clarify their own thinking on these key concepts, to inform the researcher about cultural aspects of these concepts, and to create an atmosphere of empowerment through shared learning, experience and participation.

9.5. Summative evaluation of the SP

In general, the SP was experienced positively even though the highly emotive material was at times overwhelming and distressing. Theories of change inform one that unless the present circumstances are perceived to be unacceptable and uncomfortable, the motivation to change is decreased. It may thus be beneficial to create some short-term discomfort in order for them to really empathise with the plight of vulnerable children. Many mental health practitioners, be they lay or professional, are deeply moved by individual stories. In turn, this seemed to spur their endeavours to help through offering PSS.

There was consistency in the results that emerged from the post workshop evaluations and the focus group discussions. However, the ultimate test of the effectiveness of the SP lay in the community-based initiatives. A wide variety of projects were begun with much enthusiasm and some with a great deal of success. However, the sustainability of these projects is somewhat dubious. Financial resources need to be dedicated to these activities. CBO's in general have little success in accessing funds as they have no records of financial accountability. Many do not have the experience or skills to manage finances. Volunteers are placed in highly invidious positions when they organise, for example, a sport' day for children, yet only have water to refresh and sustain themselves and the children during the course of the day. The ludicrous implications of not being able to provide refreshments is further heightened when one considers the hot and humid climate, the long, dusty distances that children walk to get to activities, and the extremely high rate of malnutrition and compromised health status. The volunteers who give so freely of their time and energy to organise these activities are caring individuals who do not have the resources to provide basic refreshments. Donor organisations will need to seriously consider appropriate methods of funding and capacity building with CBO's, as it is the CBO's who may prove to be the most valuable resource in developing resilience in vulnerable children.

The drop in numbers of dedicated volunteers from the time of the SP to the stage when the community-based initiatives occur may be cause for concern. It is possible that the 32,68% of individuals, who attended the SP, yet appeared to remain uninvolved, apply PSS principles in ways other than through the community-based initiatives. They may, for example, apply just one of the ideas within their own family context. If this were to be the case, then their non-participation in the community-based initiatives could still indicate a beneficial outcome of the SP. There is of course, no way in which these types of applications could be validly or reliably measured. Thus, the more rigorous test of the effectiveness of the SP was made on the basis of the SP participants who remained active in offering PSS. It was estimated that there are about

four dedicated people per community who continue to offer PSS activities, although it is believed that they need financial recognition, resources and rewards in order for them to sustain their efforts.

In a resource-limited context such as the current one, it may be logical to try to pre-select individuals to attend the SP, so that resources are not spent on individuals who will subsequently make minimal contribution to subsequently offering PSS activities. However, the researcher would at this stage advise against such endeavours. Many individuals reported that the material covered in the SP had a transformatory impact on them, so that those who became extremely dedicated and actively organised PSS were not necessarily the same individuals who had appeared to be the most enthused during the course of the SP. Rather it would seem that people need to be exposed to many different vehicles through which they can make active contributions to their community, one of which needs to be offering PSS to vulnerable children. This is likely to increase the probability of sustainability, as people are more likely to participate in activities that they personally find rewarding and satisfying.

9.6: Integration and summary of results on the effectiveness of the SP:

The SP has been evaluated to be an effective method (i) of sensitising community members to the psychosocial needs of vulnerable children, (ii) of developing their confidence to offer PSS, and (iii) of drawing people together in terms of developing joint plans, that they can collectively implement.

The recommendations made by the community members who participated in the post workshop evaluations as well as in the focus group discussions will be used to update and modify the SP and enhance its effectiveness as a community empowerment and development process. Nevertheless, community mobilisation programmes that aims to focus the communities' attention on the needs of vulnerable children should always proceed offering the SP. There needs to be clear commitment by some volunteers to their vulnerable children. However, a major difficulty with the SP emerges in terms of its sustainability unless resources in terms of both funds and professional supervision of the community volunteers are provided. It is also unsustainable for volunteers, who themselves live in dire poverty, to be expected to continue to offer PSS to vulnerable children when their own life circumstances are so extremely difficult and tenuous. There are strong reasons for this form of social service to be accredited, remunerated and recognised as a career path for the individuals who become dedicated and committed to the well being of children.

Chapter 10

The Second Unit of Analysis:

The effectiveness of the Structured Group Therapy Programme (SGTP)

Programme evaluations establish whether social programmes are needed, effective and likely to be used (Potter, 1999, p. 209). This aspect of the research programme involved a positivist, quasi-experimental design that evaluated the effectiveness of the structured group therapy programme (SGTP) in alleviating distress and enhancing resilience in vulnerable children. Specifically, the research questions ask if the SGTP, in combination with the SP, significantly reduces manifest symptoms, increases self-esteem and widens social support networks.

10.1. Experimental design to evaluate the SGTP:

The basic experimental design was one of obtaining baseline data on the subjects prior to the intervention, randomly assigning subjects to a variety of experimental and control conditions, implementing the intervention and then conducting the post-intervention evaluations in order to compare pre- and post-intervention data. A 4-way factorial design was applied in which there was one within subject investigation (pre-test and post-test), three between subject factors and a covariate that indicated the adversities to which the subjects had been exposed. In the between subjects analysis, the three variables investigated are age of subjects (two age groups: 8-10 year olds and 10-12 year olds), geographical area (three regions: urban township, peri-urban and rural community) and the various experimental and control conditions (See Table 10.1).

10.2. Statement of hypothesis related to the SGTP evaluation:

Note: In all instances, the term vulnerable children refers to children who have been identified as being vulnerable by community members who have participated in the SP, in consultation with the children's educators.

Hypothesis 1: Orphaned children do not manifest significantly more clinical symptoms of distress than children rendered vulnerable by other circumstances. Symptomatology was measured on a battery of psychometric tests: (i) The Trauma Symptom Checklist for Children (Townsend, 2002); (ii) The Reynolds Depression Scale (Reynolds, 1989); (iii) The Conners' Parent Questionnaire (Conners, Parker, Sitarenios, & Epstein, 1998); and (iv) The Conners' Teacher Questionnaire (Conners et al., 1998).

Hypothesis 2: Vulnerable children manifest significantly more clinical symptoms of distress than children who are considered to be non-vulnerable. The degree of symptomatology was measured on the same battery of tests as listed in Hypothesis 1.

Hypothesis 3: Vulnerable children have lower self esteem and narrower social support networks than children regarded as non-vulnerable. Self esteem was measured on the Culture Free Self Esteem Inventory (Battle, 1992). The social support networks were measured using an adapted version of the Social Support Scale (Beale Spencer, Cole, Jones, & Phillips Swanson, 1997).

Hypothesis 4: The community-based criteria of distress in children correlate with western measures of childhood psychopathology.

Hypothesis 5: Vulnerable children show significantly fewer symptoms after they have participated in the SGTP, especially if the SGTP is paired with a community-based intervention in the form of the SP. The degree of symptomatology was measured on the same battery of tests as for Hypothesis 1.

Hypothesis 6: Vulnerable children show a significant increase in self esteem and have access to more social support after they have participated in the SGTP, especially if this is paired with a community-based intervention in the form of the SP. Self esteem and social support were measured on the same instruments as for Hypothesis 3.

Hypothesis 7: Participation in the SGTP leads to a greater improvement in functioning in vulnerable children, than participation in an alternate programme of activities presented over a similar period of time as the SGTP. Improvement in functioning is defined as decreased symptomatology, increased self esteem and access to social support.

Hypothesis 8: The SGTP, paired with the community intervention in the form of the SP, is more effective in reducing symptoms and increasing self esteem and access to social support, than either of these intervention programmes run independently of one another.

10.3. Experimental and control conditions

In order to test the above-mentioned hypotheses, various experimental and control conditions were established within the partnering communities (See Table 10.1). There are three experimental groups

offering different components of the programme to children who have been identified as vulnerable: (i) Experimental Condition 1 consisted of the SP with the SGTP, (ii) Experimental Condition 2 consisted of the SP only, and (iii) Experimental Condition 3 consisted of the SGTP only. There were two control conditions: (i) Control Condition 1 offered a combination of the SP and an alternate programme of activities, attention and food to groups of randomly assigned vulnerable children - they were matched with the children in Experimental Condition 1 and Control Condition 2 for age, vulnerability status and community- of-origin; and (ii) Control Condition 2 comprised groups of children considered to be non-vulnerable -they were matched with the children in Experimental Condition 1 and Control Condition 1 for age, vulnerability status, community of origin.

Table 10.1. Overview of the experimental design:

Group	N	Pre-test data	Intervention	Post-test data	Regions
Experimental Group 1 (A and B)#	183	Yes	SP and SGTP and Community-driven initiatives	Yes	Rural Peri-urban Township
Experimental Group 2 (A and B)	165	Yes	SP and Community-driven initiatives. No SGTP.	Yes	Rural Township
Experimental Group 3(A and B)	48	Yes	SGTP only	Yes	Peri-urban
Control Group 1 (A and B)	185	Yes	SP and alternate programme of activities	Yes	Rural Peri-urban Township
Control Group 2 (A and B)	163	Yes	Non-vulnerable* children, No intervention	Yes	Rural Peri-urban Township

Note: Group A included children in the age range 8-10 years, Group B were children aged 10 - 12 years.

The reader's attention is drawn to the fact that Experimental Condition 2 only occurred in rural and township regions and not in a peri-urban area. Furthermore, children in Experimental Group 3 were not drawn from any of the communities that have thus far been described, the method of selecting these children is to be found in 10.3. below).

Non-vulnerable children included those children who appeared to the community members and educators to be well adapted and functioning well in most spheres of their lives.

Experimental Group 1 (A and B): Vulnerable children in Experimental Group 1 participated in the SGTP in seven of the nine partnering communities, where the SP had already been conducted and some community driven initiatives were being run. In each instance, a primary school was identified as the place where the SGTP would be conducted. Community members who had participated in the SP, identified and collated registers of the approximately sixty vulnerable children within the eight to twelve year age group. Group A consisted of the younger children aged eight - ten years and Group B were children aged ten - twelve years (children who were ten years old at the time of the pre- intervention data collection were allocated according to their grade, or by rounding

off their chronological age). Once informed consent had been obtained, all of the identified sixty children completed the pre-intervention assessments. The researcher then randomly assigned this vulnerable group of children to either Experimental Group 1 or Control Group 1, using a random number generating programme. The goal was to achieve pre-intervention equivalence between Experimental Group 1 and Control Group 1, with about fifteen vulnerable children forming each group.

Experimental Group 2 (A and B): SP plus community driven initiatives to offer PSS to vulnerable children: The children in this experimental condition only participated in the community- driven initiatives to offer PSS to vulnerable children and did not participate in the SGTP. This condition enabled the researcher to evaluate the effectiveness of the SP without the concomitant administration of the SGTP. Community members identified approximately sixty children as vulnerable, invited them to participate in the research, obtained informed consent and then pre-intervention data was collected in the same manner as for Experimental Condition 1 and Control Condition 1. These children were not however randomly assigned in the experimental and control groups, as the community initiatives were open for all of the vulnerable children in their area. The community members then conducted various PSS activities with them. Data collection occurred at the same stages of community intervention as in the seven communities that participated in Experimental Group 1 and Control Group 1, with an eight to ten week interval between the pre- and post-test. The people from these two (rural and peri-urban) communities understood that the SGTP would be conducted when time and resources permitted, but in the meantime they were to offer PSS (independently of the researcher) in whichever form they felt was appropriate. As such the community members regarded the children as being on a waiting list for the SGTP, and as such could be considered similar to a 'deferred control group' in terms of the community members' understanding of the process. The researcher was ethically bound to offer the SGTP to these children once this research programme was complete. Most of these children have by now participated in the SGTP with further SP courses being offered through the nine partnering communities at the request of the community members. In addition through the generous funding that has been received from the Development Corporation of Ireland and REPSSI, further communities are now being exposed to this programme.

Experimental Group 3 (A and B): Only SGTP, No community intervention: The current intervention programme had been conceived as a community-based multi-tiered approach in which it was hypothesised that the SP formed a critical ingredient of effectively offering PSS. In order to

assess the effectiveness of the multi-tiered intervention, it was necessary to run the SGTP without a concomitant community level in the form of the SP. In fact no community intervention was offered within their area. This experimental condition enabled the researcher to isolate the SGTP as a variable to be evaluated independently of the SP and the associated community involvement. Thus children in Experimental Group 3 (A and B) only participated in the SGTP without there having been any intervention at the community level. The criteria and means through which these children were identified differed from the other experimental conditions. This programme was run in only two peri-urban schools where the principals had made the request on the basis of their concern about the number of orphaned children in their school. These children were therefore identified by their educators on the basis of being orphaned within the preceding two year period, with orphanhood being defined as the death of the primary care-giver. There was no random assignment of children to this experimental condition, as they were selected on the basis of their orphanhood. There are only 48 children in Experimental Group 3. These communities have since been offered a community mobilisation and SP, since it is believed that there were sufficient grounds to ethically bind the researcher to offer the programme to these communities.

Control Group 1 (A and B): Alternate programme of intervention: Once pre-intervention data had been collected on about sixty children (identified as vulnerable by the SP participants) in each of the seven communities that participated under these experimental conditions, the children were randomly assigned into either Experimental Condition 1 or Control Condition 1. The children that had been identified as vulnerable were matched as far as possible for age, gender, community-of-origin and grade. Children in Control Group 1 participated in an alternate programme of activities that included visuo-motor activities, playing indigenous games, reading stories and doing road safety exercises. They were provided with the same food and juice as Experimental Group 1. The alternate programme of intervention aimed to control for the possible confounding variables of adult attention, activity, routine and snacks. This control group ran concurrently with Experimental Group 1. Children were informed that there were two programmes with each child being assigned to participate in just one programme for the entire fifteen sessions. Ethical considerations required that this group of children be offered the SGTP, if it was found to be an effective intervention. At this stage, most of these children have by now participated in the SGTP.

Control Group 2 (A and B): Non-vulnerable Control: Control Group 2 consisted of children matched for age, grade, school and community-of-origin with the experimental groups and who were considered to be non-vulnerable. They were selected by the SP-trained community volunteers and

at times input from the educators was also obtained. These children were considered to be non-vulnerable in terms of their life experiences and their overall presentation within the community and school. The major purpose of this control group was to establish the reliability and construct validity of the psychometric measures and to control for any community-based variables that may have had an impact on the psychosocial well-being of the children. These children did not participate in the intervention programmes, although it was discovered that some were participating in community-based activities. It would have been unethical to try and exclude them for the purpose of this research. It was seldom possible to identify as many as 15 non-vulnerable children in each age group and from each school, so there are fewer non-vulnerable children in the study than had initially been anticipated. Pre-test and post-test data on this Control Group 2 were collected simultaneously with the data collection on Experimental and Control Groups 1.

10.4. Establishing internal and external validity:

A major objective in designing research is to strive to maximise two fundamental types of validity: internal and external validity (Tredoux, 2002; McBurney, 2001).

10.4.1. Maximising internal validity:

The most basic issue in establishing internal validity is to ensure that the results are coherent, can be sustained by the design itself and can not be accounted for by alternative explanations (Tredoux, 2002). The control of the independent variables is fundamental to quasi-experimental designs since this serves the purpose of isolating the independent variable from all other variables and shows the effect of the independent variables on the dependent variables. Internal validity was considered in this study through the use of random assignment of children to the experimental and control conditions 1. Vulnerable children had equal probability of being assigned to either Experimental Group 1 or Control Group 1 since a computer programme was used to generate random numbers. Children in Experimental Group 2 were identified as vulnerable by trained volunteers who had participated in the SP, pre-intervention data was collected on them and they were then offered PSS activities that ran independently of the researcher. These children were drawn from a rural and a township community and not from a peri-urban area. Post-intervention data was collected eight to ten weeks after the completion of pre-intervention data was collected. Children in Experimental Group 3 were identified on the basis of their orphanhood and did not have a concomitant community intervention within their community. The complexities of the design are regretted, but the researcher was constrained by the logistical concerns of trying to balance the rigour required for scientific investigation with practical and real world considerations.

In summary the selection of the subjects for this aspect of the research programme is as follows:

1. Nine partnering communities were selected according to the procedures outlined in Chapter 7. The SP programme was conducted in all nine of these communities.
2. SP trained community volunteers compiled registers of vulnerable children in their own areas, concentrating on children in the eight to twelve year age group. Pre-intervention data was collected on all of these children, as well on groups of non-vulnerable children matched for community-of-origin, age, gender and grade.
3. Seven of these communities were selected, on the basis of logistical concerns, for the conduction of the SGTP during this phase of the intervention/research programme. In these seven communities, vulnerable children were then randomly assigned to participate in Experimental Condition 1 or Control Condition 1, using a computer programme that generates random numbers. In the other two communities, the vulnerable children were invited to participate in PSS community-based initiatives. Community-based initiatives operated in all nine partnering communities, with a greater range and frequency of PSS activities being offered in the two communities in which the SGTP was deferred until completion of the current research programme - this was due to the fact that the energy of the community volunteers was not diverted into running the SGTP as apprentice facilitators of the SGTP.
4. Post-intervention data collected on children from all nine of the partnering communities after similar time intervals. In this manner pre- and post-test data was collected for Experimental Groups 1 and 2, and for Control Groups 1 and 2.
5. Data for Experimental Group 3 was collected using different procedures of selection, these children came from a community in which there was no community-based intervention and they were selected on the basis of having been maternally orphaned within the preceding two year period. They participated only in the SGTP, with pre- and post-intervention data collected in a similar manner as in all of the other experimental and control conditions.

Conforming to the framework provided by Tredoux (2002), other potential threats to the internal validity of this study required attention during the design of this study:

1. *Threat of co-varying events in the community or context in which the children lived.* The number of people becoming terminally ill and dying in each community steadily increased during the time that the intervention programme was being conducted. It was not unusual for a child to experience the death of a loved one, have someone become critically ill, or be exposed to an additional major risk factor (such as sexual abuse) whilst participating in the

programme. The extremely adverse conditions in which the subjects live made it impossible to control adequately for this threat. There was however a probability that the impact of the adversities would be evenly spread across the different experimental and control groups.

2. The threat of independent natural change takes into account *the developmental trajectory of children*. This is a difficult variable to control as children are developing, dynamic little beings, in which developmental change is expected. Consideration of this threat required comparisons of pre- and post-intervention measures between the experimental and control groups.
3. *Reactive effects to participating in the study*: The major consideration in this regard, was to ensure that results could be attributed to the SGTP itself and not to alternate explanations of the change. The children in this research were potentially severely deprived of positive attention from adults and the control of this confounding variable became critical. For instance, the interaction of vulnerable children with caring, kind and attentive adults would be a strong alternative explanation for any changes that might arise, regardless of the form of the intervention. The regular routines, additional food intake and a schedule of afternoon activities were other potentially confounding variables. Control Group 1 was conducted in the seven partnering communities that were involved in this phase of the study. Children were randomly assigned to these groups and they participated in a programme of 15-sessions. Within similar size groups to the experimental conditions, children participated in small group activities, visuo-motor tasks, indigenous games, story reading, road safety exercises and snack routines. There were similar numbers of adults (compared with the experimental groups) to assist with these groups. The adult community volunteers who ran these groups were requested to show love and give the children lots of attention.

A further unexpected variable that emerged through children participating in these groups, was a labelling process, with some educators referring to children as part of 'Bev's children', or 'having Bev's food'. In some instances, this was a beneficial label as the children were considered to be a special group who would soon be functioning at an improved level. More often, however, it was detrimental with children being stigmatised as part of 'Bev's programme for vulnerable children' and were reported to have become more 'outspoken' or 'cheeky'. This was an unexpected occurrence that only emerged once the programme was being conducted.

4. *Measurement unreliability*: The evaluation of the SGTP relies on children completing self-

report inventories that were constructed to measure manifest symptoms, self-esteem, reactions to trauma and social support networks (See Appendix J). Tests with well established test-retest reliability co-efficients were selected. Trained research assistants were requested to ensure that children understood the questions and did not respond randomly. Various statistical techniques were applied to ascertain measurement reliability.

5. *Statistical regression of extreme cases:* Random assignment of children into the experimental and control condition one was used to help control the tendency for cases to regress to the mean. There were expected to be some extreme outliers, in the database, as some of the children had experienced especially extreme adversity.
6. *Participant drop-out:* Registers were taken at each session for the Experimental Groups 1 and 2, and for Control Group 1 so that the number of sessions attended by each subject could be included in the statistical analysis. The children in Experimental Group 3 could not be reliably monitored, as the registers could not reflect children who came late or left early. The community driven initiatives also occurred over various durations, time spans and has variable intensity in terms of adult to child ratios.

10.4.2. Optimising external validity:

The key consideration with respect to the external validity of a study is the use of sampling techniques that enable generalisability and representativeness, so that results can be extrapolated beyond the current study context (Tredoux, 2002). The independent variable, in this instance the SGTP, needed to be clearly stipulated so that anyone facilitating the programme would abide by similar ethics, schedules and principles. The manual was written in a way that all aspects of programme implementation had been clearly set out (Killian, 2002).

Campbell's list of potential threats to external validity (Campbell & Stanley, 1963, in Tredoux, 2002) serves as a useful checklist for external validity factors:

1. *Subject selection:* During the SP, the community volunteers participated in small group discussions that generated a working definition of vulnerability in children. There was much similarity in the definitions across the partnering communities, with external or contextual factors (such as 'having no-one to care for them', 'abuse', 'parents fighting', etc.) being regarded as critical. There were no groups who included intrapersonal variables (for example, difficult temperament, low IQ, etc.) as criteria for identifying vulnerable children.
2. After participating in the SP, community volunteers created registers of vulnerable children. The large number of children on each register made them seem unmanageable and so only those

children considered to be the most vulnerable were included. This procedure ensured that the neediest children were given priority. After the collection of the baseline data on the most vulnerable children from seven of the partnering communities, they were randomly assigned to either the Experimental or Control group 1 (Children in the other two partnering communities comprised Experimental Group 2). So as to check the community volunteers' ability to differentiate between vulnerable and not-vulnerable children, approximately ten to fifteen non-vulnerable children in each age group were identified and assessment data was obtained on them.

3. *Generalisability to other operationalisations*: The between subject factorial design takes into account the generalisability of this intervention programme to two different age groups and three types of geographic regions. The skill and experience of the facilitators and the apprentice-facilitators who conducted the SGTP could not be adequately controlled. The facilitator was always a qualified psychologist and the apprentice-facilitators were provided with extensive supervision and preparation at the end of each session with the children. The conduction of the experimental and control conditions, as well as the supervision and preparatory sessions all took place within the community setting. All of these activities took place within the communities.
4. *Generalising to other operationalisations of the outcome measures*: This threat relates to the construct validity of the outcome measures in terms of actual (as opposed to measured) decrease in manifest symptoms, increases self esteem and social support. By obtaining information from multiple sources - the children, their educators, and their primary caregivers it was hoped that the results on one measure would serve to confirm the validity of the information obtained from a different source. It was also necessary to explore the psychometric properties of the various scales that were used as a preliminary step in the data analysis. If the test was found to have unstable properties it would need to be dropped from the study as further investigation into the validity of the tests that comprised the selected battery would need internal consistency as a prerequisite for their use.

10.5. The process of subject selection and data collection:

A description of the process of subject selection, data collection and assignment of children to the different experimental and control conditions follows. The two communities who formed part of Experimental Group 2 were selected on the basis of one having a particularly active group of community volunteers, while the other had an average rate of community-based initiatives. The work of a related NPO allowed data to be collected for Experimental Group 3.

Step 1: Identifying vulnerable children: Subject selection was the responsibility of community volunteers who had participated in the SP. During the SP, there had been small group discussions

to create operational definitions on the basis of which vulnerable children could be identified. On the last day of the SP, participants developed their own plans of action. They began these community-driven initiatives to offer PSS (See Chapter 10) to the vulnerable children of their community. While implementing these activities, they usually discovered a need to compile registers of vulnerable children in their areas. After training in ethical principles, the community volunteers conducted this activity independently of the researcher. This was compiled using door-to-door surveys with community volunteers working in groups of three or four to cover specified geographic regions.

Step 2: *Selecting a venue in which to run the SGTP:* The next step was to have a collaborative consultation in which the volunteers and the researcher together identified a primary school that had many learners (within the 8 - 12 years age range) who had been identified as vulnerable. There were three exceptions to this procedure. (i) In one area, the local *Inkhozi* specified that the researcher was to work at a specific school that was in a close proximity to his home as he “watched children everyday, even those in the most terrible circumstances” (Personal communication, 2003) walking to school. The community concurred that there were many vulnerable children at this school. The SGTP was run at this school and out-of-school children from the surrounding area were invited to participate. (ii) Two schools that were approached refused permission for the researcher to work at their schools. One school cited ethical concerns as the reason for their non-participation, while the other stated that they did not want to give their school a bad name by inferring that they had many AIDS orphans. Stigmatisation of schools with many AIDS-infected children is widespread (Clacherty & Associates, 2001). Nevertheless, the perceived additional work load for educators could have also been a critical factor in this regard. Alternate schools within the geographic area covered by community-driven initiatives were readily identified and were happy to have the intervention associated with their school.

Step 3: *Gaining informed consent at a group level:* Meetings with the school principals, educators, school governing bodies and parents were attended by the researcher, research assistant and community volunteers. The intended intervention and research programme were explained in a similar vein to that adopted during CMM's. The community volunteers took responsibility for some of the presentations, with the researcher attending for the purpose of responding to research-related questions. Permission was sought to conduct the intervention on school premises, after school hours and to use school facilities such as classrooms, cloakrooms and keys. In addition, permission was sought to collect the pre- and post-intervention data during school hours on those children who were

attending the school.

The principals and educators usually also expressed a desire to assist in the process of identifying vulnerable and non-vulnerable children. Some debate usually took place between community volunteers and educators as to who should be regarded as most vulnerable. Unfortunately, this information was not captured. However, it seemed that the community volunteers usually identified children on the basis of a psychosocial index of vulnerability (social and family circumstances), whereas educators tended to use a 'learning' index of vulnerability (e.g. learning difficulties, attention deficits and mental retardation). The educators were generally poorly equipped to identify even relatively severe psychosocial hardship. It was also surprising to discover how little many educators knew about children in their classes. In three of the schools, some educators did not even know the names of the children, even when this information was required in the second half of the school year.

Step 4: The community volunteers and educators together identified children who they considered were *not vulnerable*.

Step 5: *Information letters* inviting parents and primary-caregivers of identified children to attend a meeting at the school were sent home with the children. Usually community members had already been in contact with the children and their parents or primary-caregivers. Many of the parents/primary caregivers had also attended the prior CMM's.

Step 6: *Baseline data collection:* A team of trained community-based research assistants attended the school and individually administered the questionnaires to the children and their primary-caregivers. In three areas, community volunteers elected to visit parents/primary-caregivers in their own homes over weekends as they felt that this would help them to establish their own credibility. Since the pervasive ethic of this research programme was PAR, this suggestion was accepted. The educators were given the questionnaires on the children who were to form part of the study and asked to complete these as soon as they had the opportunity to do so.

Once a child or primary-caregiver/parent was present, the first step was for the research assistant to explain the programme in detail in order to gain their informed consent. Any queries were referred to the researcher or a research assistant (not community-based) for discussion. Obtaining informed consent in an ethical manner created a challenge. The respondent needed to understand the

programme and the need for the child's attendance at all 15-sessions of the SGTP. In a context in which therapy is an unfamiliar concept, this was difficult. Special care was taken to ensure that the process was not stigmatising for the children, their families or the communities. Being able to externalise vulnerability in terms of vulnerable children being those who were experiencing especially difficult lives was useful. It was also useful to elicit positive features about individual children. The questionnaires were then completed, after which the respondents were given the opportunity to ask questions or add information, and was thanked for their participation.

Step 8: *Assignment of children to experimental and control conditions:* After the pre- intervention data collection, the vulnerable children were randomly assigned to the Experimental Group 1 or Control Group 1.

Step 9: *Conducting the programmes:* The SGTP and the alternate programme of activities were then conducted twice a week, for seven and a half weeks. In each of the four groups running simultaneously at a single school (older and younger, experimental and control), there were two to four community volunteers who were provided with extensive supervision and training. Debriefing with the community volunteers (referred to as apprentice-facilitators) after a session was found to be critically important.

Step 10: *Post-intervention data collection:* After completing the intervention programme, the children, their parents/primary caregivers and educators participated in the post-intervention data collection phase that formed the within subject factor in the design of this study.

10.6. Instruments used in data collection:

Evaluation research is the process of determining whether a social intervention has produced the intended results (Patton, 1990). The instruments selected to measure the outcomes must be relevant, valid and reliable. Working within a cross-cultural setting makes the selection of suitable instruments extremely difficult. The main issues pertaining to translation and cross-cultural applicability were discussed in Chapter 8.6. The battery of psychometric tests used in the pre- and post-intervention assessments were completed by (i) the children themselves, (ii) their primary care-givers and (iii) their educators. For ease of administration, the various instruments were collated according to these categories: (i) Child Questionnaire; (ii) Parent/Primary-caregiver Questionnaire; and (iii) Educator Questionnaire (See Appendix J, K, L). Descriptions of the various psychometric tests are given in the following sections.

10.6.1. Child questionnaires:

The measures used to assess the effectiveness of the intervention programme from the children's own perspective consisted of a series of self-report inventories that were administered individually to the children by trained community-based research assistants. They consisted of (i) Basic biographical questions; (ii) The Culture Free Self Esteem Inventory (Battle, 1992); (iii) The Trauma Symptom Checklist for Children (Townsend, 2002); (iv) Reynolds Depressions Scale for Children (Reynolds, 1989); and (v) A modified version of The Social Support Scale (Beale Spencer, Cole, Jones and Phillips Swanson, 1997).

10.6.1.1. Basic biographical questions and consent form

Once vulnerable children had been identified, their parents/primary caregivers were invited to attend meetings or CMM's to have the purpose and form of the intervention explained. Parents or primary caregivers who wished their child to participate were asked to indicate their willingness. Usually the parent/primary caregiver were then individually requested to sign informed consent forms and were then asked to respond to the parent/primary caregiver questionnaire about the child with the individualised assistance of a trained research assistant.

Children were seen individually within their school settings. If they were out-of-school children, they were invited to come to the school, usually accompanied by their primary caregivers and a community volunteer, to complete the psychometric tests and sign consent forms. Research assistants had been trained to firstly establish rapport with the child by engaging in general chatter and/or by asking the child to draw a picture (the child selected what to draw). Basic biographical questions covered the child's name, date of birth, age, grade and name of primary-caregiver. After this, the child's informed consent to participate in the programme was sought in a discussion that usually lasted between five and ten minutes. The child was then asked to sign the consent form. The administration of the collated child questionnaire then took place. Children were then given a letter explaining the programme and giving the dates and times of the sessions as a reminder to them and their parents/ primary caregivers.

Nineteen children across the seven communities initially declined to participate. The main reason given was that they were required to quickly return home after a school day so as to fulfill household tasks and responsibilities. Community volunteers offered to take on these tasks so as to enable the children to participate. Eight children accepted the offer of assistance. Eleven children felt that they

could not abdicate their responsibilities to volunteers. Regular home visits to offer individual support to these eleven children were begun and continue on a regular basis with all but three of these children whose mothers have subsequently died and the children have gone away to live with various relatives.

10.6.1.2. The Culture Free Self Esteem Inventory (CFSEI)

Self esteem is defined as a combination of positive and negative feelings and attitudes that one holds towards oneself (Rosenberg, 1979, in Marini, Roger, Slate & Vines, 2002). It reflects a child's cognitive appraisal of competence in areas that are deemed important to him or her (e.g., scholastic achievement, physical appearance). It develops cumulatively in response to the pattern of microsystemic interactions with significant others and through life experiences (Battle, 1992; Bronfenbrenner, 1997). The family has been regarded as a critical determinant of the child's earliest and continuing concepts of self (Pearlin & Turner, 1987). High self esteem has been found to positively correlate with all four of the major social support domains (parent, teacher, close friend and classmate) indicating that higher levels of perceived social support and positive regard from significant others are associated with higher levels of self-esteem (Rubenfeld, Varni, Talbot & Setoguchi, 2003). An individual with low self esteem may view the environmental context as threatening (Roy, 1976, in Marini et al., 2002) whereas individuals with high self esteem are more likely to have faith in their ability to effectively interact at various microsystemic levels. Since individuals are in constant interaction with their context, self esteem is a dynamic, constantly changing construct that evolves and responds to pressure and input (Battle, 1992). As such, self esteem represents a combination of factors including one's feelings, hopes, fears, thoughts and views of what one is, has been and will become (ibid.). Self esteem was considered to be a critical outcome measure on which to evaluate the effectiveness of the SGTP.

For this research programme, Form B of the Culture Free Self Esteem Inventory (CFSEI) (ibid.) was used. This form is relatively brief with an estimated administration time of ten minutes. Responses are of the forced choice variety with the respondents choosing either 'yes' or 'no' in terms of the applicability of the statement to themselves. Form B contains 30 self report items that are subdivided into four subcategories: (i) General self esteem (10 items) referring to overall perceptions of self worth; (ii) Social/peer related self esteem (5 items) assessing perceptions of the quality of peer relationships; (iii) Academic or school related self esteem (5 items) indicating the perceptions of academic ability; (iv) Parental or home related self esteem (5 items) involving perception of own status within the home; (v) The lie sub-test (5 items) includes an indicator of defensiveness and

validity of responses.

This test was specifically developed to meet the need for a culture free assessment tool that could be used to measure the effectiveness of intervention programmes (ibid.). The alpha co-efficiencies presented in the test manual indicate acceptable levels of internal consistency: General: 0.71; Social or Peer: 0.66; Academic or School: 0.67; Parental or Home: 0.76; and Defensiveness or Lie: 0.70. Test-Retest reliability co-efficients fall in the 0.72 to 0.98 range (ibid.) over a six month period of time. Construct validity was assessed in relation to other measures of self esteem such as the Coppersmith's Self Esteem Inventory, Beck's Depression Inventory and the Minnesota Multiphasic Personality Inventory (Battle, 1992) and in relation to health status (Carroll & Buhrow, 1994). Numerous studies have used the CFSEI. For example, Malmud, Brodsky and Gianmetta (2001) used it as correlate in an investigation of effects of witnessing violence in children, Rawon and McIntodh (1991) used it to measure the effectiveness of an experiential intervention programme, and Bynum and Dunn (1996) used the CFSEI to investigate the impact of parental divorce on children's self esteem.

Although the name of this inventory suggests that it includes "culture-free" items, it is questionable whether this is the ideal measure to quantify self esteem within a collectivist culture, in which individual perceptions of oneself are more likely to be interlinked with perceptions of others. However, the prominence of self esteem as a resilience-enhancing variable called for the inclusion of a measure of self esteem.

10.6.1.3. The Trauma Symptom Checklist for Children (TSCC):

By definition, many vulnerable children have been exposed to a variety of negative life circumstances and perhaps to some traumatic incidents that could have had a negative impact on the child. The environment in which these vulnerable children live was such that they have been exposed to a variety of extremely stressful situations that could be regarded as falling outside the realm of what could be considered normal human experiences. These include various forms of child abuse and neglect, witnessing or being the victims or perpetrators of interpersonal violence, death of loved ones, motor vehicle accidents and other disasters (Biere & Elliot, 1997; Hurt, Malmud, Brodsky & Gianmetta, 2001; Lachman et al., 2002; Mok, 1997). In the current study, the TSCC was selected for its potential to (i) elicit a broader spectrum of symptoms including trauma-related symptoms, and (ii) indicate the effectiveness of the SGTP in terms of a potential decrease in symptoms.

The TSCC is a 54-item, self-report measure for children aged 8 to 16 years, with six clinical subscales to identify particular patterns of response to traumatic incidents: (i) Anxiety, (ii) Depression; (iii) Posttraumatic stress; (iv) Dissociation with two sub-scales of overt dissociation and fantasy (these were combined in the current study); (v) Anger; (vi) Sexual Concerns. Although items related to sexual concerns can be left out of the scale, the high incidences of sexual abuse in South African communities (McKerrow, 2001) led to the inclusion of these items. All items were designed to be age-appropriate for children with normal intelligence. The TSCC was administered individually in this study, taking about ten to fifteen minutes to complete.

The authors of this test standardised it on a group of 3,000 inner city, urban and suburban children and adolescents in the United States of America (Biere & Elliot, 1997). The alpha coefficients for the clinical scales range from 0.877 to 0.89 in the standardisation sample, thereby reflecting adequate internal consistency. The predictive validity for normative and clinical samples was relatively good (ibid.). There are two in-built validity measures on the TSCC: (i) under-responsiveness (UND) measures abnormally low endorsement of commonly experienced symptoms and difficulties and (ii) hyper-responsiveness (HYP) measures excessive reporting of rare or infrequently occurring symptomatology. The scales have been used in diverse empirical studies that have served to establish both the construct validity of these scales and the test-retest reliability (Brady & Caraway, 2002; Gorman, Kennedy and Hamilton, 1998; Mok, 1997; Scott, 1998; Shaw, Lewis, Loels, Rosado & Rodriques, 2000). It is considered to be particularly useful in evaluating the effectiveness of interventions with traumatised children (Brady & Caraway, 2002), and in discriminating trauma related symptoms in different sub-categories of vulnerable children in both first and third world contexts (Gorman et al., 1998; Mok, 1997; Shaw et al., 2000).

10.6.1.4. The Reynolds' Depressions Scale for Children (RDSC):

The measurement of depression is an important component in the overall evaluation and understanding of children's mental health and well-being (Reynolds, 1989). It was essential to focus on childhood depression since this form of childhood disorder is (i) a frequently reported sequella of parental illness and death (Wicks-Nelson & Israel, 1997); (ii) associated with poverty (McLoyd, 1998); (iii) empirically linked to maternal depression and other forms of childhood dysfunction (Wicks-Nelson & Israel, 1997); and (iv) is related to the experiences of separation, loss and major changes in one's life. Any of these phenomena can lead to overwhelming helplessness, hopelessness and the negative triad of cognitive attributions associated with depression (Beck, 1991). Symptoms associated with childhood depression and dysthymia include social withdrawal, somatic complaints,

low self esteem, irritable mood, lack of concentration, failure to make expected gains in weight, and loss of enjoyment in activities that were previously experienced as pleasurable (APA, 1994).

The Reynolds' Depression Scale for Children (RDSC) was the third test in the collated child questionnaire. It is a self-report questionnaire that can be administered individually or in groups to children aged 8 - 12 years (Reynolds, 1989). The 30-item test has been written at a second grade literacy level and takes approximately ten minutes to complete. All questions, with the exception of the last one, ask the child to consider the frequency with which they experience certain symptoms on a four-point Likert scale ranging from "almost never" to "all the time." The last item asks the child to indicate which of a series of expressive faces reflects their general emotional status with drawings that depict sad to happy states. This last item was not included in the analysis in the current study as many children experienced difficulty in understanding the drawings.

Using a cross-cultural standardisation sample of 1,600 children, the RDSC shows strong reliability and validity, with an internal consistency coefficient using Cronbach's alpha of 0.92 (Reynolds & Graves, 1989). and split half reliability of 0.89 (Reynolds, 1989). The RDSC exhibits test-retest reliability of 0.82 and 0.85 for 2-week and 4-week intervals respectively (Ibid.). Concurrent and convergent validity have been demonstrated with the Hamilton Depression Scale with a correlation coefficient of 0.83 (ibid.) and the Children's Depression Inventory ($\alpha = 0.87$) (Kovacs, 1979). Validity has been demonstrated through extensive content, construct and criterion-related studies (Reinecke & Schultz, 1995). Criterion-related validity studies with clinical samples, report strong support for the RDSC with diagnostic and semi-structured clinical interviews (Reynolds, 1989; Reinecke & Schultz, 1995; Shain et al., 1990). The RDSC has frequently been used as a measure of the effectiveness of treatment programmes and for children entering alternate care (Reinecke & Schultz, 1995; Schick & Runyan, 2003). Mazza and Reynolds (1999), using the adolescent version of the RDS, demonstrated that parental death is strongly associated with both trauma-related and depressive symptoms.

10.5.1.5. The Social Support Scale (SSS):

The presence of a social support network ameliorates against vulnerability (van der Merwe, 2001). Vulnerable children are particularly in need of a social support network, for both material/physical needs and for psychosocial support. The 8-item self-report questionnaire developed by Beale Spencer, Cole, Jones and Phillips Swanson (1997) provides an indication of the child's perceptions of the availability of social support within three contexts: (i) family members including mother,

father, siblings and other members of the extended family; (ii) school including the educator and the school principal; (iii) peers, including same-aged children as well as close friends. The categories of grandmother, community members and ministers were added in the current research due to their relevance to this context.

The child is asked to respond at various levels. First, he or she is asked if they have this person in his or her life. This question takes into account the possible absence of a potentially significant source of social support to the child. Then, the child is asked to indicate how helpful he or she regards that person to be in providing emotional support, instrumental help and fun and satisfaction (Beale Spencer et al., 1997). The SSS was effectively used by van der Merwe (2001) in her South African study of the relationship between access to social support and child behaviour outcomes.

10.6.2. Parent/Primary-caregiver and educator questionnaires

The parent/primary-caregiver and educator questionnaires used in this research programme had some overlapping information (Appendices I and J). The primary-caregiver questionnaire covered (i) Biographical questions giving relationship to the child, age of primary-caregiver, household composition, physical health status and the child's strengths and difficulties from the perspective of the primary-caregiver; (ii) Exposure to deaths and other adversities related to psychosocial risk; (iii) 5 questions developed on the basis of key indicators of childhood distress as defined by the communities themselves (During the translation and training of research assistants these were frequently associated with childhood distress and thus had the potential to provide a set of community-based criterion for childhood pathology); (v) 3 questions pertaining to the child seeing images of deceased people - again this seemed to be a cultural phenomenon that emerged during the earlier stages of the programme and the outcome of this experience seemed to be related to either feelings of comfort or fear, so it warranted further exploration; and (vi) Connor's Parent Rating Scale (Conners', 1989) (See Appendix K).

The educators were also asked to complete a questionnaire on each child. Studies have shown that children in distress are likely to behave differently at home and at school (Kazdin, 2000). The collated Educators' Questionnaire consisted of (i) Biographical information about the child including length of time that the educator had known the child, an assessment of the child's overall performance at school, a record of the child's attendance at school over the previous month, physical health status, strengths and concerns about the child as well as an open-ended question about the child's strengths; (ii) Biographical information about the educator including years of teaching

experience, the number of children in the educator's class, educational and marital status, parental status, religious affiliation and personal experience of family members who were ill or had died of HIV/AIDS related illness; and (iii) The Connor's Teachers Rating Scale (Conners', 1989) (See Appendix J).

The Conners' Parent and Teaching Rating Scales are widely used research and clinical instruments that are considered to be responsive to changes in the child's behaviour (Conners, 1973 ; Conners, Parker, Sitarenios & Epstein, 1998). The National Institute of Mental Health in USA has included them in the standardised battery for childhood psychopharmacological studies (Conners et al., 1998) because they are economic, quick to administer, reliable and moderately valid (Schacher, Sandberg & Rutter, 1986, in Conners et al., 1989). Being able to obtain responses from both the home and school situations, using similar measures has added to their popularity. They have been used in many cross-cultural studies (Conners et al., 1998).

Although best known in South Africa for the Hyperactivity Indices, these scales offer scoring categories for various forms of emotional and behavioural difficulties in children. The CPRS - 93 and the CTRS - 39 were used in the current study (See Table 10.2). In the interests of brevity, the psychometric properties are presented in Table 10.2 below. Responses are factored into six clinical subscales on the teacher rating scales and eight subscales on the parent rating scales. One can also obtain scores relating specifically to classroom behaviour, group participation and attitude towards authority. All of these scales were considered to be potentially useful in the assessment of vulnerable children.

In the current research context educators are generally considered to be demotivated and disengaged with individual children in their classes (Kolisang & Lourens, 2003). This meant that a number of problems could arise from using educators as informants about children's behaviour: (i) In poorly-run classrooms, many children could be regarded as being difficult or deviant. Alternatively in large classes, deviance and disruption may be regarded as normative, in which case very few children would be identified as difficult (Conners et al., 1989). (ii) Although psychometric tests have the appearance of being objective in nature (in terms of the assigned numeric values), they represent the educators' subjective assessments of the children. (iii) The generic problems associated with rating scales still apply. For example, all rating scales are subject to halo and rater effects. The halo effects are especially likely to be problematic as vulnerable children may internalise difficulties and present as compliant or well-behaved whereas they are actually depressed or anxious. Nevertheless after an

extensive review of the apposite literature, Barkley (1986, in Conners et al., 1989) endorses the usefulness and cost-effectiveness of teacher rating scales despite the relatively low inter-rater reliability figures obtained in various studies. Ratings of emotionally disturbed children by teachers and independent observers correlated 0.39 on conduct problem scale; 0.73 on the hyperactivity scale; 0.39 on the inattentive/passive scale; and 0.52 for total deviance (Kazdin, Esveltd-Dawson & Loar, 1983, in Conners et al., 1989).

When rating children who exhibit troublesome, externalised behaviour, the inter-teacher ratings correlations are better ($\alpha = 0.66$ on the conduct problem scale and $\alpha = 0.70$ on the hyperactive/inattentive scale). There is a corresponding decrease in the correlation on the depressed mood and anxious-to-please scales, with $\alpha = 0.3$ (Glow, 1979, in Conners et al., 1989). The subscale and informant variations need to be considered in the interpretations of the scores obtained on the teacher scales.

Table 10.2. Conner's Rating Scales for parent/primary-caregiver and educator:

Characteristics	Parent Rating Scale	Teacher Rating Scale
Form - No. of items	CPRS - 93	CTRS - 39
Norms	T Scores by age and gender for 6 - 14 year olds	T scores by age and gender for 4 - 12 year olds
Standardisation sample	683 children aged 6 - 14 years, subsequently used internationally and cross-culturally Revised version standardised on 8,000 with cultural and ethnic diversity (African-American, Asian-American, Caucasian, Hispanic/Latino, Native-American) from within USA and Canada	9583 Canadian children aged 4 to 12 years, subsequently used internationally and cross-culturally.
Clinical subscales	a) Conduct Disorder b) Anxious Shy c) Restless-Disorganised d) Learning Problem e) Psychosomatic f) Obsessive-Compulsive g) Antisocial h) Hyperactive-Immature	1) Hyperactivity 2) Conduct Problem 3) Emotional Overindulgent 4) Anxious Passive 5) Asocial 6) Daydream-Attention Problem
Inter-rater reliability	Mean correlation between mothers and fathers 0.51, with no significant differences between their scores.	On hyperactivity index 0.7, on other subscales moderate agreement of 0.54.

Characteristics	Parent Rating Scale	Teacher Rating Scale
Test-Retest Reliability	Over one year range from 0.4 for the Psychosomatic subscale to 0.7 for the Immature-Inattentive + hyperactive-impulsive subscales (Glow, Glow, & Rump, 1982). The range of Test-Retest Value: 0.47 to 0.85	Over one month (ranging from 0.72 to 0.91). Moderate over one year (ranging from 0.53 for Conduct Problem to 0.33 for Depressed Mood)

Difficulties were encountered in this study with the administration of the educator questionnaires: (i) Many educators did not know the names of the children in their classes. This necessitated bringing a child to the educator so that the educator would know about whom he or she was responding. (ii) Many educators regarded the completion of questionnaires to fall outside of their job descriptions. In one school, they obtained union support not to complete questionnaires. (iii) Some educators superficially responded, resulting in much similarity in an educator's responses across different children, or pages in which crosses had been filled in right down a single column. Relatively few educator questionnaires are included in the data sets. These difficulties will be discussed further in the results section of this dissertation.

In practice research within such disadvantaged and difficult contexts was a challenge. One of the major oversights in developing this programme, was that educators were not specifically targeted for the SP. The researcher's experience was that approximately 50% of the educators were neither co-operative nor involved. Most resided outside of the geographic region in which they taught. Their terminology when discussing vulnerable children frequently reflected a lack of care and commitment towards children whom they simply regarded as difficult or problematic. There were also occasion when it became clear that the educators distrusted the structure of the SGTP which they perceived as monitoring their school and the hours that they were working. Since the SGTP would commence 20 minutes after the completion of a normal school day, it became apparent that some schools finish their school day at irregular times or cancel certain school days. The volunteers and the psychologist would at times arrive at a school (with the catering supplies) to discover that school had been closed early that day and all of the children had already been sent home, or that there was a school excursion, or cancellation of school for the day. Communication between the researcher and the educators was not optimal. However, there were exceptions to these generalities. Approximately half of the educators were committed, involved and eager. These educators were supportive and sensitive to the circumstances of individual children, knew their learners by name and frequently enquired about progress or spontaneously provided feedback about changes in the child or the child's circumstances.

The pre- and post-intervention data phases were in fact highly chaotic with varying degrees of motivation, skill and commitment in the children, their primary-caregivers and their educators. The community volunteers were eager to help but frequently lacked the organisational foresight needed to manage this process adequately. The inevitable compromise in the quality of the data was hopefully off-set by obtaining similar data from multiple sources and in the capacity-building within a community in terms of developing research skills, compassion for vulnerable children and empowering communities to take responsibility.

10.7. Data Analysis

All data was entered into MSExcel spreadsheets, that were later exported into SPSS spreadsheets. The normative data based on standardisation samples from Eurocentric cultures was regarded as potentially being irrelevant to the present study so raw scores were entered into the database. After all of the data had been captured, careful verifying of the accuracy of the data took place. Some errors in coding and some incidents of careless entry were identified and were cleaned. The data cleaning process delayed the analysis of the results by about a month, since very careful checking was required.

Data was then analysed using the SPSS computer programme (Version 11). The stages in data analysis started with adjusting all reverse scored items across the psychometric tests, then exploring their psychometric properties using item analysis, correlation matrices and factor analysis. This cautious approach to data analysis was necessary given the fact that the subject sample differed substantially from the standardisation samples, and that the children in this research were living in extreme adversity, where the community conditions were steadily deteriorating in terms of the number of people who were becoming ill or dying. Once the structure of the tests had been investigated, it was possible to take the analysis to the next step of using one-way analysis of variance, and then more sophisticated multivariate analysis. The researcher sought the assistance of a more experienced researcher who was familiar with the assumptions and strengths of the various statistical tests.

Chapter 11

Summative Evaluation: Structured Group Therapy Programme for Children

The SGTP is a 15-session structured group therapy programme for vulnerable children (Killian, 2002). It was evaluated in the positivist tradition using a 4-way factorial design with a single within subject variable of pre and post intervention, and three between subjects variables (experimental/control condition, geographic region, age of subjects) with a covariate of exposure to adversity. The context of this research meant that the design was somewhat constrained by various factors that required special consideration in the analysis of the results. The tests were imported from first world conditions, administered by inexperienced, though trained, community-based research assistants, and the circumstances of the subject sample was extreme in the sense that the children were experiencing deaths, parental illness, hunger, abuse and other extreme psychosocial risks while the research was being conducted.

After providing a basic description of the sample, the various psychometric tests are carefully explored to examine their structure and appropriateness for the current research context. Once the suitability of the tests has been ascertained, the hypotheses are investigated.

11.1: Description of Sample:

741 children participated in this aspect of the study. There were 595 vulnerable children of whom 319 (43%) were maternal orphans and 276 (37.2%) were identified as vulnerable but were not orphans. 146 (19.7%) children were considered by the community members to be non-vulnerable (See Figure 11.1). There were 358 (48.3%) males and 381 (51.6%) females in the sample, roughly equally distributed across the three categories of children ($\chi^2 = .648$, $df = 2$, $p < .723$). The children were all within the age range of eight to twelve years, with a mean age of 10.05 years ($SD = 1.57$) and there was no difference in the mean ages of the three categories of children ($F(2,737) = 1.089$, $p < .337$). 51.1% of the children was allocated to the younger (eight to ten years olds) and 48.9% were allocated to the older (ten to twelve year olds) groups.

The sample was drawn from seven of the partnering communities with 2.3% ($n = 17$) being out-of-school children who resided in the community surrounding the school. All of these children began attending school after the intervention. Given that school entrance is legally supposed to occur at age seven years, one would have expected the sample to be largely from grades two to six (See Table 11.1). Although the children in the three categories were of similar age, the non-

vulnerable group was on average in a higher grade (Mean = 4.41) than the vulnerable children (Mean = 3.79) and orphans (Mean = 3.75) ($F(2,734) = 7.62, p < .001$).

Figure 11.1. Sample distribution by vulnerability status and gender:

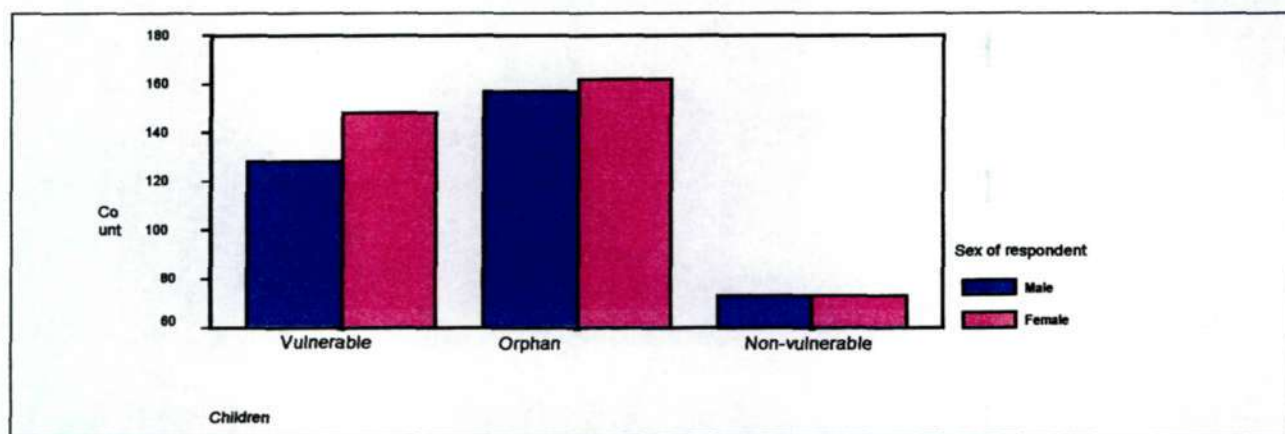


Table 11.1: Current grade of the subject sample:

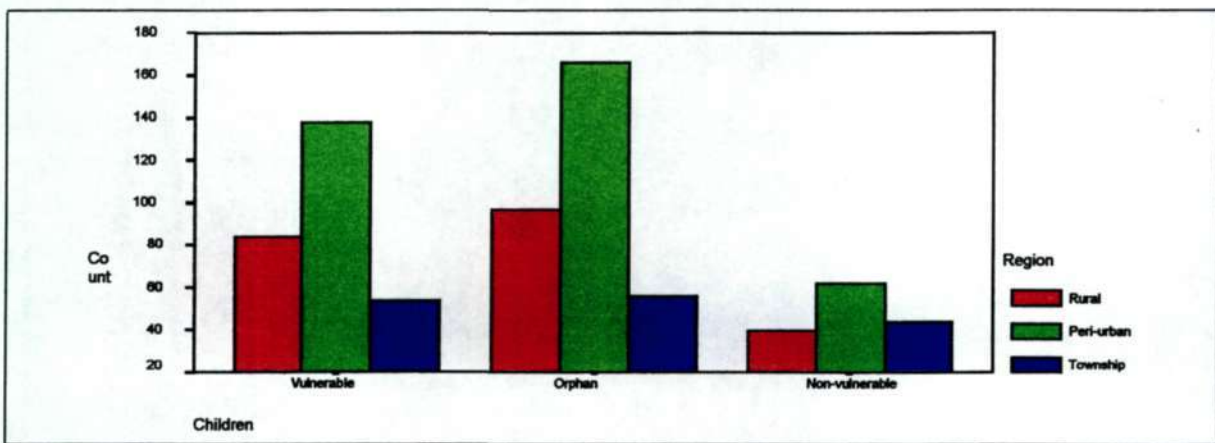
GRADE	N	%
Grade 1	18	2,4
Grade 1	61	8,2
Grade2	89	12,0
Grade 3	144	19,4
Grade 3	151	20,4
Grade 5	95	12,8
Grade 6	131	17,7
Grade 7	48	6,5
Missing data	4	0,5
Total:	741	100

The majority of the subjects came from peri-urban communities ($n = 366, 49,3\%$), followed by rural areas ($n = 221, 29.8\%$) and townships ($n = 154, 20,8\%$). The non-vulnerable children were slightly over-represented in the township subsample and under-represented in the peri-urban subsample, while the orphans were slightly under-represented in the township subsample ($\chi^2 = 10.19, df = 4, p < .037$) (See Figure 11.2).

Children who had been identified as vulnerable from seven of the nine partnering communities were randomly assigned to either Experimental Group 1 (SGTP + SP) or Control Group 1 (alternate programme of activities + SP), with approximately equal numbers participating in each of these two conditions. Thus, there were seven groups, for each of the younger and older age

groups, who followed the conditions for Experimental Group 1, and seven groups for each of the younger and older age groups who followed the programme for Control Group 1. The average number of children participating in each group was 13. A sample of children considered to be non-vulnerable was drawn from the same seven communities to form Control Group 2 (Non-vulnerable). Difficulties were experienced in identifying those children who had not been exposed to major adversities, due to the extremely adverse conditions that prevailed in the partnering communities, resulting in a slightly smaller group of non-vulnerable children.

Figure 11.2: Distribution of subjects by vulnerability status and geographic region:



Children from the other two other partnering communities formed Experimental Group 2 (only community intervention). They participated in community-based initiatives run by community members who had participated in the SP. Experimental Group 3 (SGTP) comprised 48 orphaned children who participated in the SGTP, with no concomitant community-based intervention within their community. The sample distribution in terms of allocation to the different experimental and control conditions is presented in Table 11.2. The reader will note that there is an uneven sample distribution across the different cells. This created some challenges for the statistical analysis. Experimental Group 1 and Control Groups 1 and 2 came from two rural, two peri-urban and three township regions. Experimental Group 2 had no township residents, and Experimental Group 3 was drawn from only peri-urban areas (See Table 11.2).

Attendance figures apply to only three of the conditions: Experimental Group 1, Experimental Group 2 and Control Group 1. The SGTP is usually conducted over fifteen sessions. There was an average attendance at 12,2 sessions. Attendance statistics only reflect attendance at the programmed sessions and do not include additional sessions or organisational meetings held in advance of commencing the programme. A few children, predominantly from Control Group 1,

attended very few sessions, so that the standard deviation (std dev = 3.3) reflected the negative skewing in terms of poor attendance of some of the subjects. Incidents of child rape (at least three children had been raped, with the alleged rapist being the father of another child participating in the programme in one community; while in another community a child had been raped by an uncle) required attention, so that the daily programmes in two of the communities were deferred to the next session (and attendance at these extra sessions were not included in the attendance statistic).

Table 11.2: Distribution of subjects by condition and geographic region:

Condition	Total	Rural	Peri-urban	Township
Experimental Group 1 (SGTP + SP)	184 (24,8%)	49	82	53
Experimental Group 2 (SP)	163 (22%)	79	84	0
Experimental Group 3 (SGTP)	48 (6,5%)	0	48	0
Control Group 1 (Alternate Programme)	183 (24,7%)	49	82	52
Control Group 2 (Non-vulnerable)	163 (22%)	44	70	49
Total	741 (100%)	221	366	154

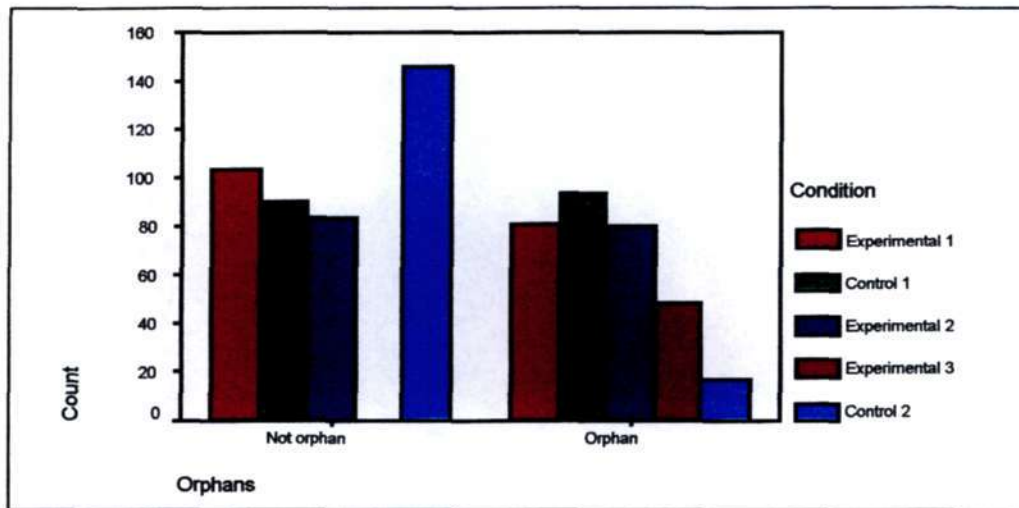
Table 11.3: Assignment of orphans to the experimental and control conditions:

	Condition					Total
	Exp 1	Exp 2	Exp 3	Control 1	Control 2	
Vulnerable + Not Orphaned	103	83	0	90	0	422
Vulnerable + Orphaned	81	80	48	93	17*	319
Non-vulnerable	0	0	0	0	146	146
Total	184	163	48	183	163	741

* Orphaned but regarded by trained community members as non-vulnerable.

The subgroup of children who were maternal orphans was of particular interest. Children were assigned to the various experimental and control conditions in seven of the partnering communities, as presented in Table 12.3, according to their vulnerability status (and not being orphaned). The reader will recall that Experimental Group 3 subjects were selected on the basis of their orphanhood status, whereas for the other conditions, community members, trained during the SP, identified vulnerable children and those considered being non-vulnerable. Of particular interest is that 17 orphaned children were identified by community members as being non-vulnerable (10,4% of the non-vulnerable group). Consideration of their psychometric profiles confirmed that this was a valid categorization of these children.

Figure 11.3: Assignment of orphans to the various experimental and control conditions:



There were no accurate attendance registers for children in Experimental Group 2 (only SP). Children in Control Group 2 (non-vulnerable) were not supposed to participate in any structured activity, although it was discovered that some had been participating in several of the community-based initiatives. There were no reliable records of how many of the children in Experimental Group 1 or Control Group 1 were attending the community-based initiatives. It was impossible to adequately control for this variable due to the differing forms of community-based initiatives, children arriving and leaving at different times, and varying child to adult ratios. Since the research ethic had been based on PAR, it was necessary to trust that community members were regularly conducting the activities that were being reported. It would have been counter-productive to try and control for attendance at these sessions, or to prioritise research needs over the children's best interests by imposing exclusionary conditions to keep the research design pure. Researchers who work in real world contexts frequently encounter these sorts of difficulties (Kazdin, 2000; Robson, 2002).

Only 548 (74%) of the children's primary caregivers completed the battery of psychometric tests. The mean age of the primary caregivers was 42,9 years (SD = 16, 31). The large standard deviation reflected the range of people who reported as primary caregivers, with 26,6% being grandmothers and at the other end of the age spectrum 2,1% were siblings (1,3% brothers and 1,9% sisters) from child-headed households. The relationship of the primary caregiver respondents to the children is presented in Table 11.4. Most primary caregiver respondents (93,5%, n=490) lived with the child.

Table 11.4: Relationship between primary caregiver respondents and the children:

RELATIONSHIP	N	%
Mother	250	33,7
Grandmother	146	19,7
Father	37	5,0
Foster Mother	4	0,5
Foster Father	10	1,3
Sister	5	0,7
Brother	7	0,9
Maternal Aunt	24	3,2
Maternal Uncle	14	1,9
Paternal Aunt	24	3,1
Paternal Uncle	11	1,5
Cousin	5	0,7
Neighbour	4	0,5
Other	2	0,3
No primary caregiver (information/permission obtained from community leader)	5	0,7
Total	549	74%
Missing data (The Parent / Primary Caregivers Questionnaires was not completed)	193	26,1
Total (Including missing data):	741	100

11.1.1. Description of children's problems and experience at community level (see Appendix K):

The total child sample consisted of 741 child subjects (including those whose parents/primary caregivers did not complete the questionnaire) who were categorized into three groups: (i) children identified as vulnerable and orphaned – referred to simply as orphans in the following discussion for the sake of brevity of expression and not in a derogatory tone; (ii) children identified as vulnerable and were not orphans – referred to simply as vulnerable children in the following discussion; and (iii) children identified as non-vulnerable who resided in the partnering communities – referred to simply as non-vulnerable children in the following discussion (see Figure 11.4). The distribution of category of children by geographic region is presented in Figure 11.5 showing that proportionally more orphans were resident in rural and peri-urban areas, but that all categories of children were identified within each geographic region.

Figure 11.4: Distribution of the 741 children by category:

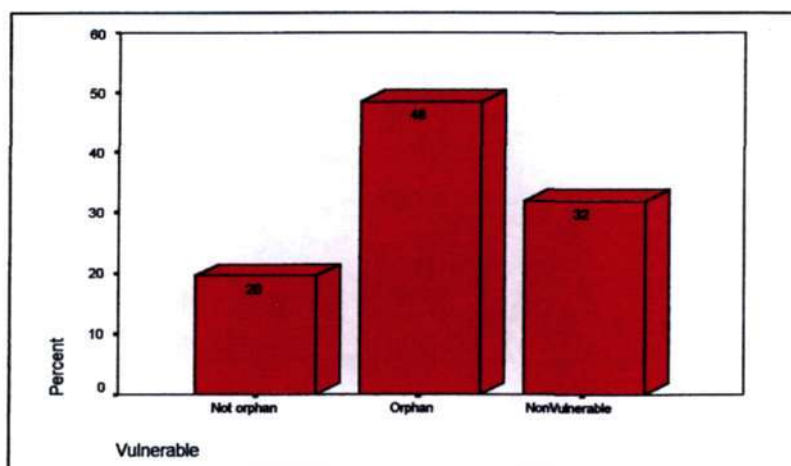
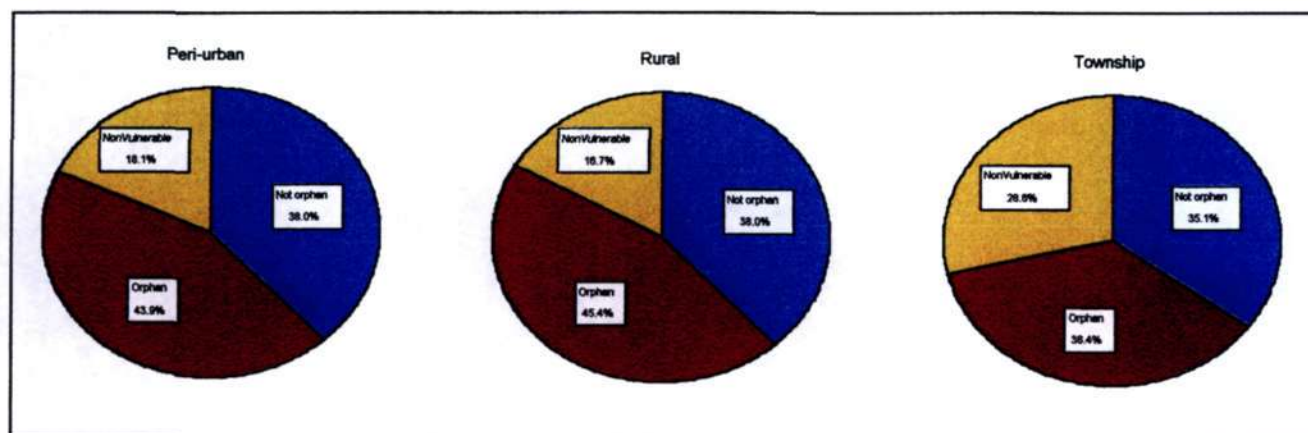


Figure 11.5: Proportional representation of children by category for each of the geographic regions.



The results presented in the following section were obtained from the 549 respondents who completed the Parent / Primary Caregiver Questionnaire (Appendix K). The reader is reminded that the parents/primary caregivers from only seven of the partnering communities were requested to complete these questionnaires (see Chapter 10). The data presents the respondents' opinions about the child's exposure to adversities, experience of death, health status, positive/appealing qualities and concerns about their children at the time of the pre-intervention data collection phase.

The major focus in this section will be discerning differences in the life experiences of children resident in the partnering communities. The subgroup of children who were vulnerable and maternal orphans was of particular interest as there are many debates about whether it is ethical, or wise, to target only orphans for intervention and neglect children rendered vulnerable by other

circumstances. Therefore, Hypothesis 1 was concerned with differentiating between orphaned children and other vulnerable children in terms of their psychosocial profiles.

11.1.1.1: Prevalence of different forms of adversity in the child subjects:

In order to facilitate the formulation of macrosystemic policies and to develop appropriate microsystemic interventions (Bronfenbrenner, 1986), one needs to understand the nature of adversity to which the child subjects were being exposed. The data used for this analysis is based on the 549 parent/primary caregiver responses to open-ended questions as well as categories of risk that were defined as possibly being prevalent in the partnering communities (Appendix K, Questions 13 – 15) (see Table 11.5 and Figure 11.6). There was much homogeneity in the responses leading to a relatively straightforward categorizing of the information. However, to try to make the information more meaningful in terms of impact, it was decided to include the first mentioned phrase in describing the adversity in response to the open-ended question in the following table and figure, even though the respondents had not been asked to rank order the adversities experienced by the children. This is a shortcoming in questionnaire design. At times this led to the ambiguous situation in which the response was categorized into two categories: for example, funerals and looking after sick relatives, presented as a single phrase. This problem arose in 15,66% (n=86) of the responses. And so the actual phrasing was used to decide which categories to include, with the first mentioned adversity/ies being regarded as the one/s that were of greatest concern for the primary caregivers/parents. There obviously are problems with this approach, since the various forms of adversity are usually inter-related.

It is useful to group the various adversities into those that (i) appear to be HIV/AIDS-related in terms of their relationship to illness and death (“worried about the death of loved ones” – including those who had died or who may die, “looking after sick relatives” – often the recipients of HBC, and “funerals” – a category that included often speaking, worrying, or having nightmares about funerals); (2) poverty-related conditions included financial difficulties and inadequate care – a category that was not adequately tapped by the questions that were posed in this section of the questionnaire; (iii) other social/community problems consisting of abandonment, child abuse and neglect, child sexual abuse and rape, excessive parental drinking, motor vehicle accidents, enemies (included statements indicating that the respondents felt that the child, or his or her family, had been bewitched, that other children were jealous, or that the child had people who regarded the child as an enemy); and (iv) getting sick frequently. The last category is regarded as being independent of the HIV/AIDS-related conditions, since gastro-

enteritis was the most frequently spontaneously mentioned illness. The frequency distributions are presented in Figure 11.7.

Table 11.5: Children's exposure to various forms of adversity, using the first mentioned forms of adversity:

Form of adversity*	Freq	%	% by category of child		
			Vulnerable	Orphan	Non-vulnerable
Non-Response	133	17.9	18.4	18.2	33.6
Abandoned	9	1.2	1.6	1.1	1.8
Money problems	77	10.4	9.0	13.9	14.5
Enemies	27	3.6	4.1	3.6	6.4
MVA	90	12.1	16.7	13.2	10.9
Worried about death of loved one	139	18.8	22.4	25.7	10.9
Getting sick frequently	12	1.6	0	0.4	10.0
Rape victim	19	2.6	1.6	2.5	7.3
Inadequate care	5	.7	0.8	0.4	1.8
Parents drink excessively	29	3.9	5.3	5.4	0.9
Looking after sick relatives	36	4.9	6.1	7.5	0
Funerals	59	8.0	13.9	8.2	1.8
Total	635	85.7			

Figure 11.6: Exposure to adversity by the three categories of children

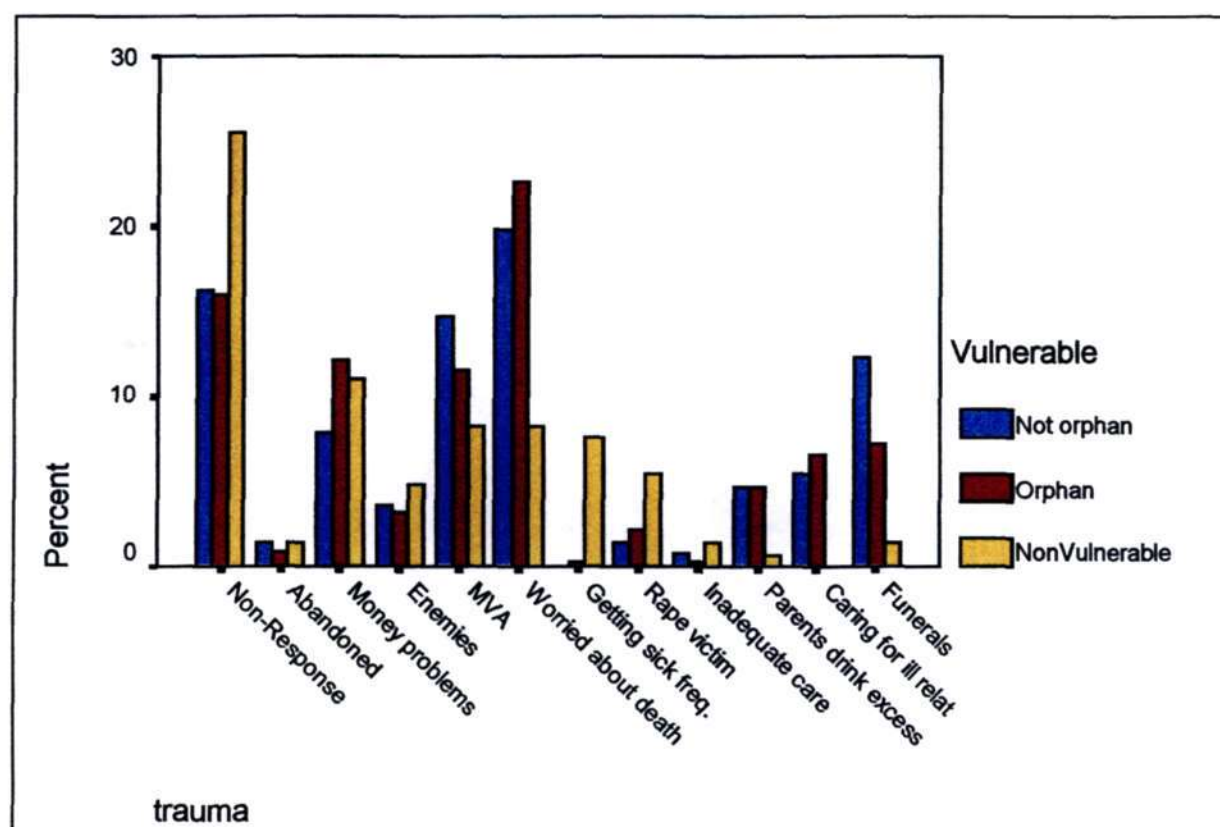
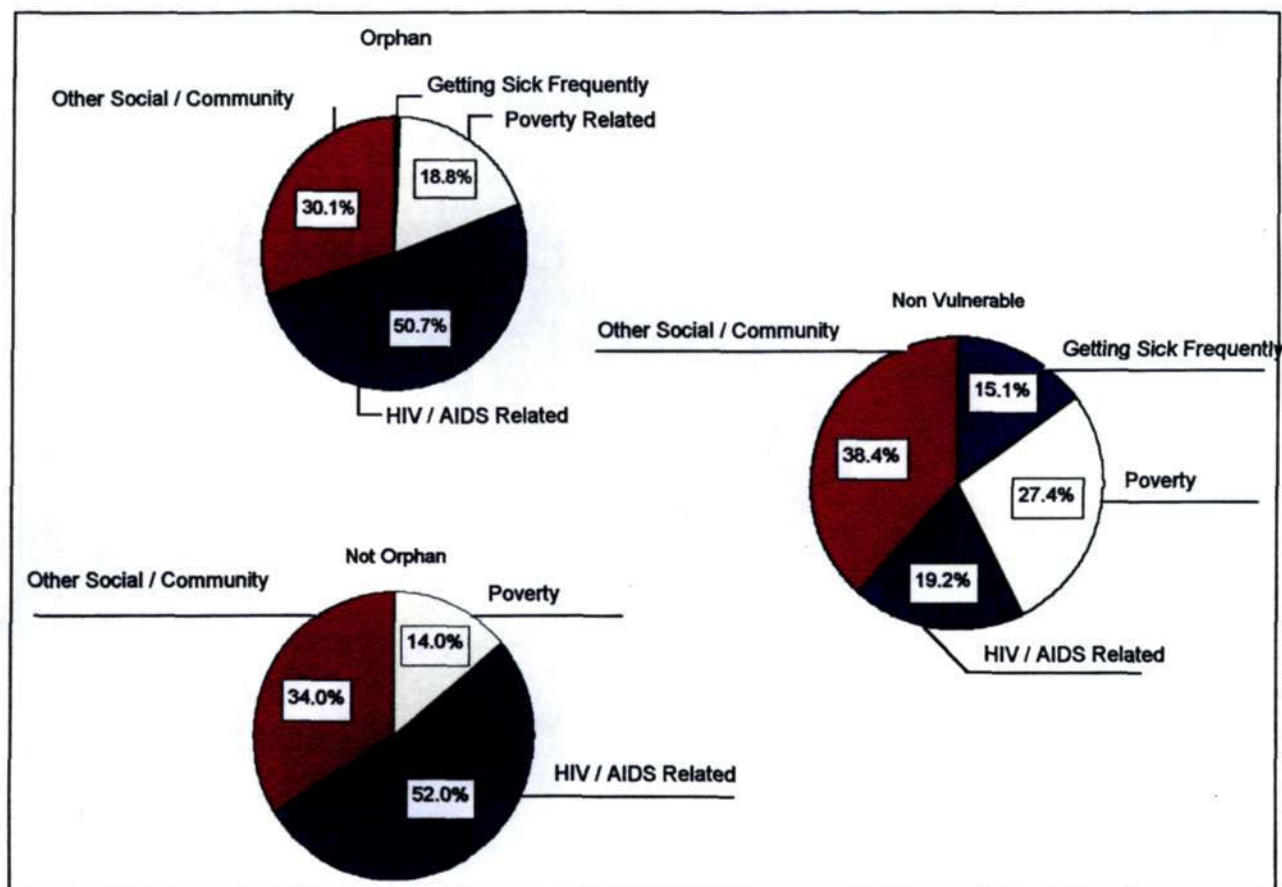


Figure 11.7: Proportional percentage frequency of spontaneously mentioned adversities, by category of adversity and category of subject:



It would seem that the parent/primary caregiver's focus shifts according to the status of the children, in addition to these being reflective of the actual issues that maybe affecting children. While all categories of children are reported to experience poverty-related conditions, it is of concern, though logical, that the children who are vulnerable, but not orphans are reported as suffering from proportionally the most HIV/AIDS related adversities. This suggests that this vulnerable group of children have begun their journey of adversity as set out in Chapter 3 of this dissertation. The orphaned children are being exposed to proportionally greater adversities reflective of dysfunctional societies. The non-vulnerable children are not immune to the impact of the pandemic since they frequently get sick - a factor that could have psychosomatic origins in that both their caregivers worry about their children becoming sick or in the children who may be somatising their distress. In poverty-stricken communities, with the onslaught of the HIV/AIDS pandemic, it seems that children may go through the adversities brought by poverty, then stress over illness and their own health status, then become more directly affected by the HIV/AIDS related adversities after which they face a multiplicity of societal and social problems.

11.1.1.2.: Health status of the children from their parent/primary caregivers' perspectives:

In order to ascertain the form of health problems being experienced by the children in the partnering communities, the parents/primary caregivers were asked if the child was currently experiencing any health difficulties. Again the homogeneity in responses led to a simple process of categorising these responses into relatively few categories. This data is presented in the form of percentage of responses for each form of health problem that was spontaneously mentioned by the parents/primary caregivers (See Appendix I, questions 10 and 11) by category of children. It would seem that the non-vulnerable children experience fewer health problems than the other categories. Proportionally the vulnerable children are experiencing similar sorts of health problems, with fewer non-vulnerable children's parents reporting health difficulties. By far the most frequently mentioned health problems were skin rashes ($n = 243$) and coughing ($n = 139$), with significantly fewer reports of other forms of health difficulties (headaches $n = 28$; tummy aches $n = 40$). It is concerning that only orphans were reported as being infected with worms/parasites. There were 32 instances in which the fact that the child was being raised by an ill caregiver was mentioned as a health concern. It was also concerning that only 22 parents/primary caregivers positively framed that their child was healthy, while 48 respondents gave similar information by saying that the child had no health problems. This cumulatively means that only 12,75% of the parent/primary caregivers regarded their children as being free of health difficulties. There is no clarity of how the various problems are diagnosed or labelled or for that matter what they mean. For example, arthritis is not a malady usually associated with children. It must be remembered that this categorization is based simply on the parents' and primary caregivers' description of the health problems. In Figure 11.8, the various subtypes of problems are combined with (i) respiratory problems including coughing, TB and asthma; (ii) nutritional including malnutrition and poor eating habits; (iii) dermatological including skin rashes, scabies, and wounds that would not heal; (iv) frequent headaches and tummy aches being regarded, perhaps with some undue bias, as being reflective of potential psychosomatic problems, (v) developmental includes problems such as slow learner, and slower than other children, and (iv) various maladies such as arthritis, joint problems, fractures, etc. being included in the other category.

11.1.1.3: Positive qualities in the children from their parent/primary caregivers' perspectives:

There was an opportunity to use this data collection procedure to obtain a description of the strengths or qualities that were positively valued by the parents and primary caregivers. This could be considered to partially reflect the qualities that parents in this cultural group may wish to

instil in their children. Again the qualities are presented by proportional representation in each of the categories of children, to ascertain if different qualities are admired in the different categories of children (see Figure 11.9). The most interesting features to emerge in this regard are that (i) there was a higher proportion of non-vulnerable children who were described as active sportsmen, perhaps suggesting that the vulnerable children (be they orphaned or not) are less encouraged to participate in sporting activities; (ii) non-vulnerable children were more likely to be described as being respectful; (iii) it would also seem that being helpful was a characteristic more frequently described amongst vulnerable children; (iv) playing with other children, being hard workers and neat were qualities especially valued by the caregivers of vulnerable children, whereas this did not feature prominently for the non-vulnerable group of children.

Figure 11.8: Proportional frequency of health problems by category of children:

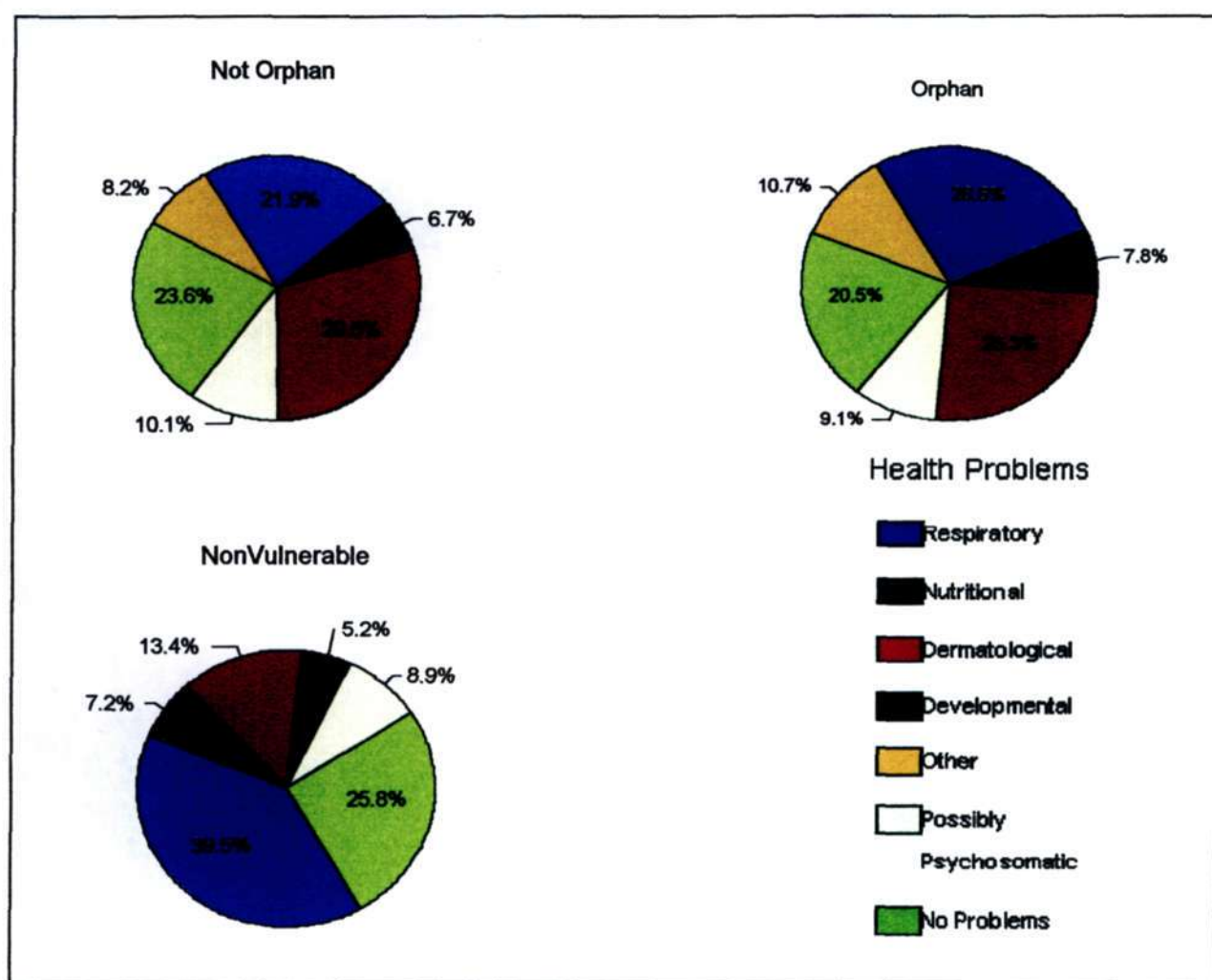
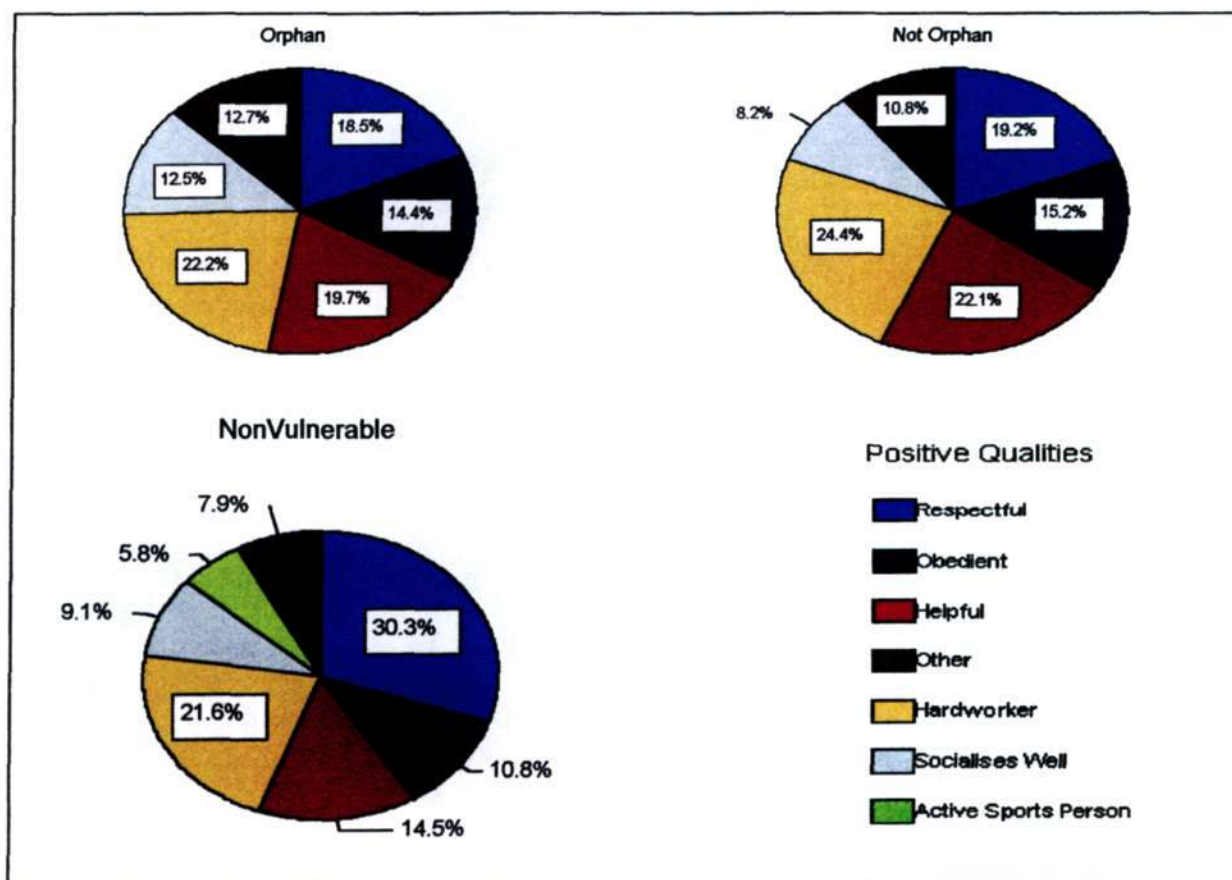


Figure 11.9: Positive qualities as described by the parents'/primary caregivers:



11.1.1.4: Concerns about the children from their parent/primary caregivers' perspectives:

In addition, the parents/primary caregivers were asked to express their concerns about the child from a more psychosocial perspective (Appendix K, Question 13). Open-ended questions were again used, the responses categorized, and then comparisons made across the groups of children. The categorization of these responses was much more complex than in the previous two sections, and so it is not useful to provide categories of responses in this instance. It was particularly the vulnerable and orphaned children who were reported as "lazy", with very few non-vulnerable children being reported to be "lazy". Interestingly being shy was a concern expressed mainly by the parents/primary caregivers of non-vulnerable children. Most of the primary caregivers who were caring for orphans who had been categorized as non-vulnerable seemed to be sensitive to the needs of orphans by expressing this as a concern for the child. Enuresis was a frequently reported problem with it occurring in 27% of the total population group, with no discernible differences between the various categories of children.

In summary, it would seem that most of the children in this study have experienced multiple adversities, many of which derive from the extreme poverty in which they live. Nevertheless, the

vulnerable children experience more severe forms of psychosocial risks, with those children who are maternally orphaned having experienced relatively similar profiles of adversity to those children who are rendered vulnerable due to other circumstances of difficulty in their young lives. The results would suggest that vulnerable children need to be regarded as an at risk group, without special consideration of orphanhood as a criterion for selecting children for the purpose of intervention.

11. 2: Educators' responsivity:

One of the flaws of the current intervention was that insufficient attention was given to draw educators into the process in a consultative and participatory manner. Many of the educators perceived this research/intervention programme to be an additional responsibility that they were unable to shoulder for various reasons. There is little doubt that the educators in this country are under enormous stress in terms of curricula shifts, perceived changes in their conditions of employment and de-motivating work circumstances. Although most schools were willing to have the intervention based on their school premises, they had little enthusiasm and so many did not engage in the process.

While the researcher was negotiating with the principals, educators and school governing bodies for permission to work in the schools, it was made clear that the educators would be required to complete questionnaires on all identified children for both the pre-intervention and post-intervention phases. Both the researcher and the educators had underestimated the magnitude of this task. Many of the educators completed the questionnaires in a manner that rendered them invalid (either with all responses placed in the same column or with too many missing items). These responses lacked face validity and so were not entered into the database. Some educators admitted to having begun the process with a negative attitude. As a result, the response rate for educators was only 12.2% (n=90) for the pre-intervention and 29.3% (n=217) for the post-intervention phase. It was interesting to note that more educators completed questionnaires during the post-test (n=217) than the pre-test (n=90), suggesting that educators became more co-operative once they understood the process or saw beneficial changes in the children. The net result was that only 8.6% (n=64) of the educators completed both the pre-test and the post-test for specific subjects. With this very high subject mortality (Tredoux, 2002), it was unlikely that the educators who did complete questionnaires could be regarded as a representative sample of either the children or of the educators. There were also insufficient subjects across the different cells for a multivariate analysis. The extremely low response rate renders any statistical analysis meaningless and so no further analysis on these questionnaires was conducted.

11.3: Adversity Index:

The Adversity Index was included as a covariate in the summative evaluation of the SGTP. Vulnerable children had been identified on the basis of the operational definitions that were developed during the SP, in terms of the child's exposure to risk variables. The description of the form of adversity was provided in Chapter 10, in this instance only the number of risk variables was included. So, consistent with the empirical findings of the cumulative impact of adversities (Luthar & Cicchetti, 2000; Sameroff et al, 1997), an index of the child's exposure to various adversities was obtained by simply adding the number of adverse situations to which the CPQ respondents' confirmed that the child had experienced (See questions 16 and 17 of the CPQ). It is important to bear in mind that the parent or primary caregiver may not have been aware of some of the adversities to which the child had been exposed. For example, if a child was being sexually abused, it was presumably unlikely that the parent/primary caregiver would know about this. Scores ranged from zero to two, on a 3-point Likert scale with 'Definitely', 'Possibly/Maybe' and 'Definitely Not' as the range of possible responses. The Adversity Index consisted of the unweighted sum of scores to the risk exposure questions, with a potential range of 0 to 36. In this instance, the score was not divided by the number of items on the scale.

The number of deaths to which the child had been exposed was recorded separately. The research assistants had been requested to obtain information pertaining to the first three deaths that the respondent mentioned, although information relating to fewer or more deaths was given in some instances. This index was somewhat crudely calculated (it cannot accurately take into account the effect of the death on the child) as follows: (1) Close family members (mother, father, grandmother, grandfather, brother and sister) were given a weighting of two, while other relatives, friends and neighbours were scored one; (2) The recency of the death was taken into consideration by scoring two if the death had occurred within the preceding six months, one if it had occurred between six months and year previously and zero if it had occurred more than a year ago. The closeness and recency values for each experienced death were multiplied to yield weighted and summed scores. The descriptive statistics for the two adversity indices are presented in Table 11.6. The reader will note that this information was only obtained once, during the pre-test. The mean score for the number of risk factors was a high 8,08, while the mean death experience score was also exorbitantly high for a child sample.

The high adversity index, combined with the extremely high index of experience of death leaves one in no doubt as to the vulnerable status of these children. This was confirmed by our clinical experience, when children spoke about family members who had died or had become critically

ill. It further suggests a strong confounding variable that would impact on the outcome of the intervention. The continued exposure to adversity and grief could negatively impact on children's functioning and therefore on their scores on the various measures. Since this data was categorical in nature (as opposed to interval) it was not possible to run item analysis or to explore the construction of the scale before using it in the multivariate analyses.

Table 11.6: Descriptive data for measures of Adversity and experience of death:

Adversity and Death Experience	N	MEAN	SD	α
Adversity Index	548	8.08	1,89	0,852
Experience of death	548	19,9	10,28	0,91

11.4. Examining psychometric properties: Item analysis and scale construction:

The psychometric tests that were used to evaluate the SGTP were developed, standardised and validated in contexts that are very different to the current research setting. Therefore, the initial step in data analysis involved statistical examination of the psychometric structure of these scales using item analyses, reliability coefficients, correlation matrices and factor analyses to examine the scale structures. The results of all of these analyses are to be found in Appendix N.

11.5: Intercorrelations between measures

The measures considered in Chapter 10 and Appendix N were used as the dependent variables in repeated measures ANOVA designs, in which a series of exploratory bivariate correlations matrices were produced for all indices associated with each of the measures used in the study. These correlation matrices were used to determine:

- (i) If there was any redundancy between the different indices derived from each measure? Preliminary investigation of the various measures had yielded 26 indices as potential candidates to determine the existence of experimental effects. However, since the experiment-wise error rate would be inflated by conducting numerous inferential tests, it was necessary to determine whether it was possible to derive a defensible subset of indices to use as dependent variables.
- (ii) If the measures were stable over time? Correlations between pre-test and post-test scores provided both an indication of the reliability of the measures and the degree to which the within-subjects design would enhance the sensitivity of the analysis of variance procedures.

The intercorrelations that were used to establish potential redundancy and time-stability are reported in Appendix O.

11.6. Experimental effects for depression:

Analysis of variance procedures, using the total summed score on the RDSC-Total were used to determine if any of the experimental conditions significantly reduced depression in the children. Specifically, the question investigated here is whether the SGTP paired with the SP and community interventions was more effective in reducing depression than either the SGTP or the SP run independently of the other. Thus, the main interest was in the interaction between the within subjects RDSC effect and Condition. The original plan was to conduct a multivariate repeated measures ANOVA with one within-subjects factor - pre-test and post-test scores on RDSC – and three between subjects factors - Condition, Age group and Region, and use the Adversity Index as a covariate. However, the data was problematic in many respects, so it was necessary to conduct a number of preliminary investigations and make modifications to the final analysis. In the end, the results clearly indicated that the SGTP and the SP were effective in reducing depression in Experimental Groups 1 and 2.

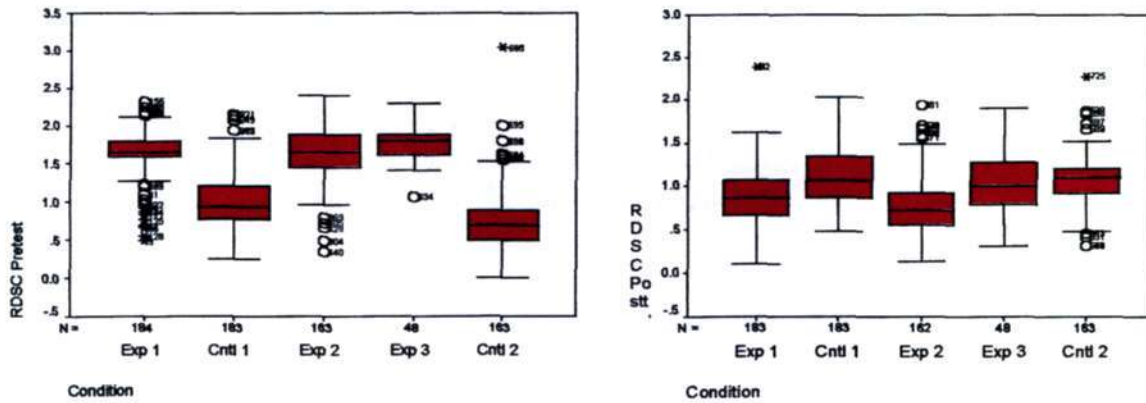
11.6.1: Testing assumptions

Before testing the first assumption, the equality of the variance-covariance matrix, one should always check univariate normality and homogeneity of variance (Hair et al, 1995). Tests of univariate normality allow one to judge whether the data satisfies the second assumption of MANOVA, vis. multivariate normality.

The basic descriptive information for pre-test and post-test scores for the RDSC by experimental/control condition, for each of the regions, separated into the younger and older children (Appendix P). The first problem encountered was the empty cells for Experimental Group 2, which has no rural sample, and Experimental Group 3 that has no rural or township sample. In addition, there are substantial differences in the variances of the scores in the different cells.

Box plots were constructed for pre-test and post-test RDSC scores crossed with each of Condition, Region and Age. All six sets of plots revealed a similar troubling picture of (1) outliers, (2) skewed non-normal distributions, and (3) heteroskedasticity. To illustrate, since the RDSC by Condition interaction is our prime concern, the box-plots for RDSC by Condition are presented below (Figure 11.10).

Figure 11.18: Box plots for pre- and post-test RDSC scores by Condition:



On the basis of the boxplots four extreme outlying scores were excluded from further analysis. Since, in many respects the sample was an extreme one, it was decided to retain the other less extreme outliers in the analysis. The outliers for Experimental Group 1 in the pre-test were majority low scorers, and so their effect would be to reduce the mean pre-test depression scores, and thus have the effect of making it more difficult to detect a significant reduction in scores in the post-test condition.

To deal with the problem of heterogeneity of variance and non-normality, a series of logarithmic and square root transformations were undertaken. However, because the data for the different groups were skewed in different directions, the distributions for the transformed variables were no better than the distributions for the raw data. Finally, difference scores were computed by subtracting post-test RDSC scores from the RDSC pre-test scores. These scores were negatively skewed for the groups and the variances were unequal. None of these transformations helped. Since ANOVA procedures are robust in the face of departures from the assumptions of normality and homogeneity of variance, it was decided to proceed with the Repeated Measures ANOVA, but to set *alpha level conservatively at $\alpha = .02$, and to be cautious in interpreting the results* (Hair et al., 1990). To deal with the problem of empty cells it was decided to drop Experimental Group 3 from the next step in the analysis since this group had no data for rural or township areas and had considerably fewer subjects than the other conditions.

11.6.2. Multivariate repeated measures ANOVA for Depression

A Repeated Measures MANOVA was conducted using SPSS. The design included 1 within-subjects measure (Pre-test and Post-test RDS Scores) and three between-subjects independent variables: Condition (Experimental Groups 1 and 2, and Control Group 1 and 2), Age group

(younger, older) and Region (rural, peri-urban, township). The Adversity Index was included as a covariate.

The data suffered from the problem of heteroskedasticity. Accordingly, the Box test found that the covariance matrices were not equal ($p < .001$). Nonetheless, as argued above, the analysis was conducted with due caution. The outcomes of the tests for the different multivariate criteria (i.e. Wilks' Lambda, Hotelling's Trace, Roy's Largest Root) all agreed exactly. However, since Pillai's Trace is the most robust of the multivariate criterion – "significance level based on it is reasonably correct even when the assumptions are violated" (SPSS, 1990, p. 95) – only this criterion is reported in the Table 11. 7.

Table 11.7: Within-subjects multivariate effects for RDSC:

EFFECT	Pillai's Trace	F	DF	Signif	Partial Eta Squared	Observed Power
RDSC Total Score	.51	30.31	1, 568	.000*	.051	1.00
RDSC x Adversity	.002	1.29	1, 568	.256	.002	.206
RDSC x Condition	.467	165.64	3, 568	.000*	.467	1.00
RDSC x Region	.016	4.57	2, 568	.011*	.016	.775
RDSC x Age	.000	.023	1, 568	.876	.000	.053
RDSC x Condition x Region	.016	1.90	5, 568	.093	.016	.645
RDSC x Condition x Age	.01	2.00	3, 568	.113	.010	.516
RDSC x Region x Age	.00	.027	2, 568	.973	.000	.054
RDSC x Condition x Region x Age	.022	2.61	5, 568	.024	.022	.803

Using the relatively stringent significance level of .02, there are three significant effects: the main effect for RDSC, the RDSC by Condition interaction, and the RDSC by Region interaction (Shown in bold in Table 11.7). In each case, the design has more than sufficient power to detect a significant effect; and the most striking feature in Table 11.7 is the large effect size for the RDSC by Condition interaction, $\eta^2 = .467$. The effect for the covariate, Adversity, was not significant indicating that the inclusion of this variable did not enhance the sensitivity of the design. As expected, the observed power for the non-significant effects was below the optimal value of .80. This means that one cannot conclude that these effects do not exist. However, since our purpose was to reject the null hypothesis for the RDSC by Condition effect – i.e. to say that the *intervention* was effective in reducing the depressive symptoms – the inability to reject the null hypothesis for these more peripheral effects was not a major concern.

The between-subjects effects indicate whether the average of the RDSC pre- and post-test scores differ across the cells of the independent variables. Table 11.8 shows that there were three interesting and significant effects: for Condition, Age, and for the interaction between Condition

and Age (shown in Bold). Somewhat troubling, these effects indicate that the random assignment of subjects to groups did not result in equivalence across the various groups. Nevertheless, since the within-subjects MANOVA essentially tests for *differences in the change in RDSC between groups*, this non-equivalence does not obscure the meaning of the within-subjects effects reported above.

Table 11.8: Between Subjects Multivariate effects for RDSC:

	Type III Sum of Squares	Df	Mean Squares	F	Sign.	Partial Eta Squared	Observed Power*
Intercept	49.627	1	49.627	869.402	.000	.605	1.000
Adversity Index	0,005	1	.005	.090	.764	0,000	.060
Condition	3.600	3	1.533	126.861	.000	0,124	1.000
Region	0,088	2	.044	3.769	.464	0,003	.181
Age	0,519	1	.519	9.100	.003	0,016	.853
Condition x Region	0,287	5	.057	1.006	.413	0,009	.361
Condition x Age	0,719	3	.240	3.199	.006	0,022	.856
Region x Age	0,189	2	.094	1.654	.192	0,006	.349
Condition x Region x Age	0,239	5	.048	2.838	.523	0,007	.302
Error	32.423	568	.057				

- Computed using $\alpha = 0,05$

11.6.3. Simple effects and groups differences for Depression

Since the between-subjects effects are not of prime interest, they will be considered only briefly. Tukey's HSD test (Table 11..9) indicated that the Experimental Groups 1 and 2 had similar RDSC means on average, and that these were higher than the Control Group 1 mean, which in turn was higher than the Control Group 2 mean. Since Control Group 2 was selected to represent a group of relatively functional children (the non-vulnerable children), the depression scores were anticipated to be lower.

Table 11.9: Simple effects of depression scores (Tukey's HSD):

Condition	N	Subset		
		1	2	3
Control Group 2	160	0,9002	1,0745	1,2050
Control Group 1	183			
Experimental Group 2	162	1,000	1,000	1,2569
Experimental Group 1	182			0,198
Sign.				

Means for groups in homogenous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square (Error) = 1,059.

Tukey's HSD uses Harmonic Mean Sample Size = 171,073, and Alpha = 1,05.

The marginal means for the Condition by Age effect are presented in Table 11.10, together with confidence intervals. These indicate that the interaction is due to Control Group 1, for which the younger groups have significantly lower scores than the older group, whereas for the other groups, there is no difference between the means of the younger and older groups.

Table 11.10: Depression scores by Condition and Age

Condition	AGE ALLOCATION	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Exp. 1	Younger	1,258	0,028	1,203	1,312
	Older	1,266	0,025	1,218	1,314
Exp. 2	Younger	1,191	0,027	1,139	1,244
	Older	1,216	0,027	1,162	1,269
Control 1	Younger	0,990*	0,026	0,940	1,041
	Older	1,163*	0,027	1,111	1,215
Control 2	Younger	0,874	0,026	0,824	0,925
	Older	0,921	0,030	0,861	0,981

* Based on modified population marginal mean.

Table 11.11 reports the marginal means and simple effects of the interaction between the pre- and post-test RDSC scores (the within-subjects factor) and Region. Figure 11.11 shows that this is an ordinal interaction. All groups show significant decreases from pre-test to post-test. The interaction is due to the fact that the effect is larger for the rural groups than for the other two groups. This was an interesting finding since the rural groups expressed much relief at being the recipients of services as they are usually a socially excluded group.

Table 11.11: Depression scores by Region:

Region	Pre- and Post-test	Mean	Std. Error	95% Confidence Level	
				Lower Bound	Upper Bound
Rural	Pre	1,271*	0,049	1,174	1,367
	Post	0,887*	0,045	0,798	0,976
Peri-Urban	Pre	1,247*	0,021	1,206	1,287
	Post	0,993*	0,019	0,955	1,037
Township	Pre	1,200#	0,032	1,138	1,263
	Post	1,006#	0,029	0,948	1,064

* Covariates appearing in the model are evaluated with the Adversity Index = 16,381.

Based on modified population marginal mean.

Table 11.12 and Figure 11.12 report the results for the two-way interaction between the within-subjects (pretest versus posttest) condition and Condition. This effect helps us understand the

impact that the different experimental and control conditions had on the mean depression scores of the groups.

Figure 11.12: Interaction effects within subjects (pre and post) by Region:

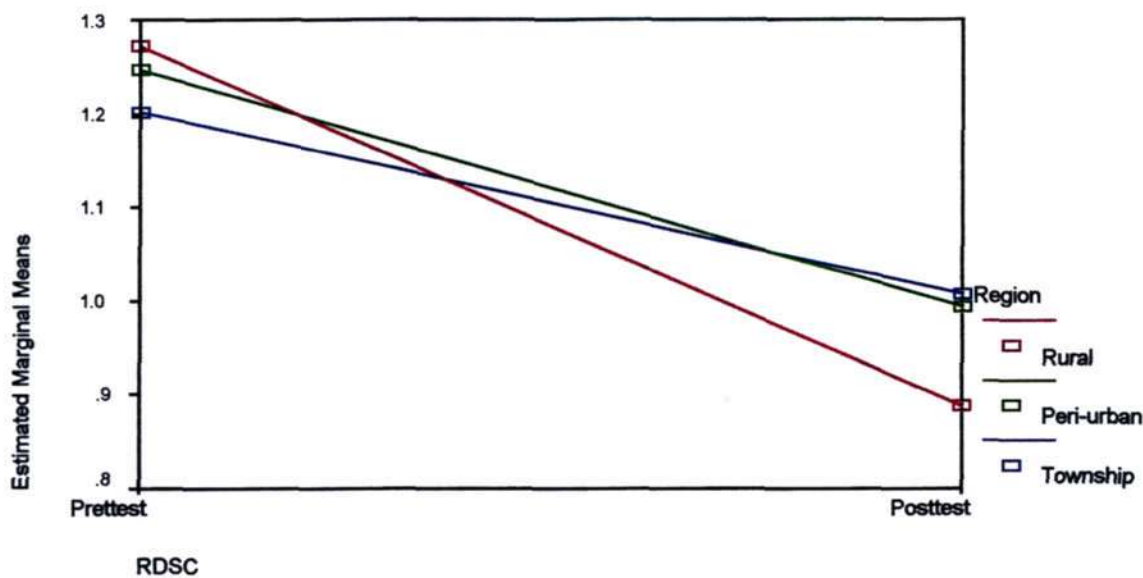


Table 11.12: Depression scores by Condition (excluding Experimental Group 3)

Condition	Pre-/Post-test	Mean	Std. Error	95% Confidence Level	
				Lower Bound	Upper Bound
Exp. 1	Pre	1,701*	0,030	1,642	1,759
	Post	0,836*	0,027	0,782	0,890
Exp. 2	Pre	1,637*#	0,028	1,581	1,693
	Post	0,746*#	0,026	0,694	0,797
Control 1	Pre	1,007*	0,028	0,952	1,062
	Post	1,123*	0,026	1,072	1,174
Control 2	Pre	0,758*	0,064	0,632	0,883
	Post	1,056*	0,059	0,941	1,172

* Covariates appearing in the model are evaluated with the Adversity Index = 16,381.

Based on modified population marginal mean.

The reader will recall that Experimental Group 3 was excluded from this part of the analysis because of missing cells for higher order effects between Condition and Area. To determine the effects for Experimental Group 3, simple effect analysis was conducted including all groups. As can be seen, Experimental Group 3 scores followed the trend of Experimental Group 1 and 2, showing a reduction from the pre-test to post-test (Figure 11.13).

Figure 11.12: Interaction effects within subjects (pre and post) by Condition:

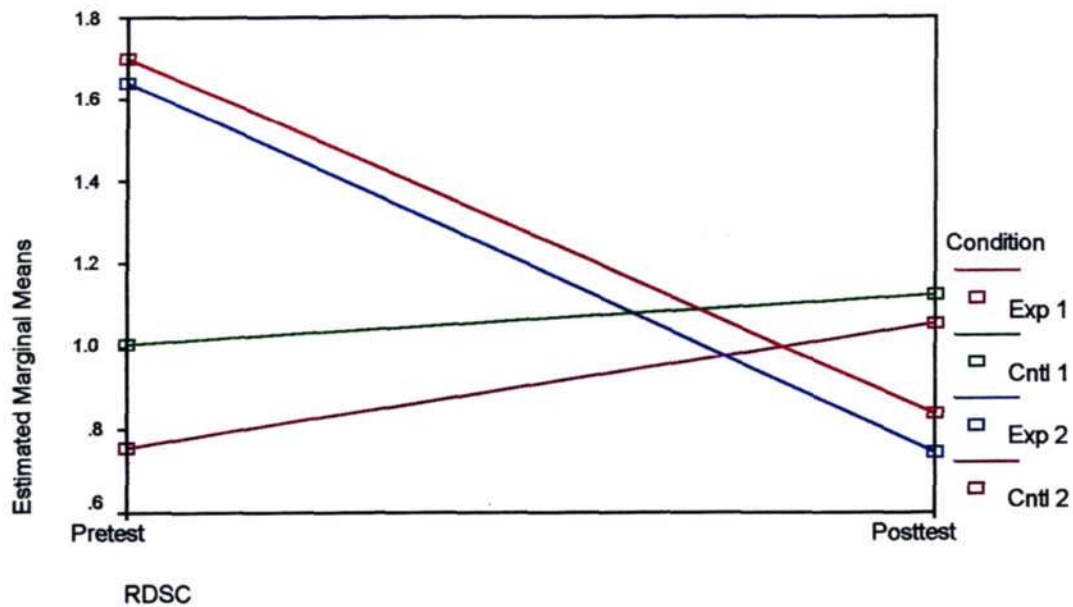
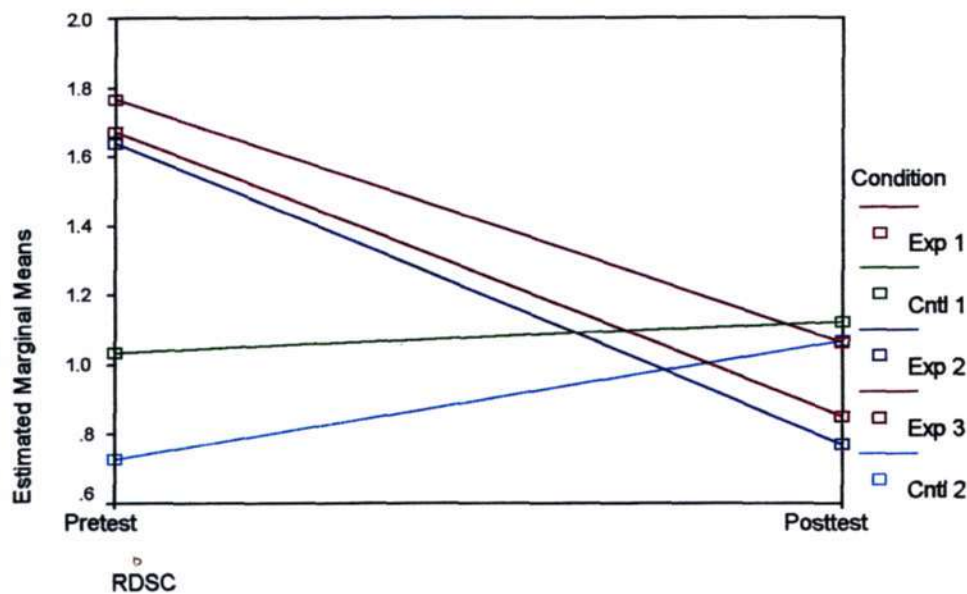


Figure 11.13: Interaction effects within subjects (pre and post) by Condition:



The multivariate data analysis for the within-subjects interaction effects on the RDSC showed a decrease in depressive symptomatology for the three experimental groups, whereas an increase has occurred for the two control groups. This increase is not significant in the Control Condition 1 children, but is significant for Control Condition 2 children. The RDSC within-subject interaction effect for region was also significant with the rural children showing the greatest decrease in reported depressive symptomatology. This indicates that regular interaction with adults in their own communities either in the form of the SGTP, or in the form of the community-based initiatives, or in combination, is effective in reducing depressive symptomatology. The children in Control Condition 1 showed a slight, but insignificant, increase in the degree of their

depressive symptoms. Interestingly the non-vulnerable children, some of who actually reported that they were feeling left out and excluded, showed a slight increase in depressive symptoms. In most of the seven communities in which the non-vulnerable children lived, the presence of the researcher and a team of therapists was a highly significant and unusual event that enjoyed much interest and attention. These severely neglected communities were very excited to see motor vehicles arrive in their communities on a regular basis. This may have had the effect of elevating the status of those children and adults who were involved with this unusual occurrence – the intervention programmes.

11.7: Experimental effects for clinical symptoms measured on the TSCC:

Multivariate analysis of variance, using the total summed scores on the TSCC were used to determine whether and which experimental conditions had an effect in reducing self-reported symptoms in the children: (1) the community intervention paired with the therapy programme for children (Experimental Group 1); (2) the community intervention (Experimental Group 2); or (3) the SGTP (Experimental Group 3). The design included one within-subjects factor – pre-test and post-test scores on TSCC and three between- subjects factors: Condition, Age group in terms of the younger and older children, and geographic region. The Adversity Index was used as the covariate. In terms of the hypotheses, the main concern was with the interaction for the within-subjects effect on the pre- and post-test TSCC scores and Condition. A number of preliminary investigations were conducted. The results clearly indicated that the programme was effective in reducing the clinical symptoms reported by the children.

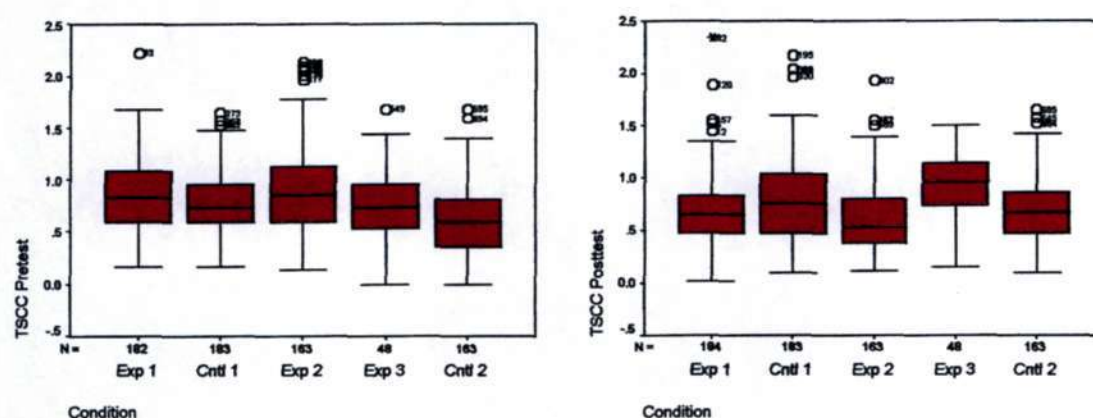
11.7: Testing assumptions:

Three interesting features were revealed while testing the assumptions on the TSCC (see Appendix Q): (1) the cell means differ substantially and do appear to be patterned across the independent variables; (2) the condition of homogeneity of variance has not been met, but rather that variances differed substantially across cells; and (3) there is variation in the number of subjects per cell. Although the largest cell is twice the size of the smallest cell – a requirements to make the ANOVA robust¹⁴ – the problem of some empty cells across the regions again created some challenges. There were no township subjects in Experimental Group 2 and no rural or township subjects in Experimental Group 3.

Boxplots showed that the differences in variation between the various experimental and control conditions were not too large (Figure 11.14). In addition, although the distributions were skewed,

they were all skewed in a similar direction, further suggesting that the ANOVA calculations would be robust and provide a good indication of significant effects (Howell, 1997). A series of transformations were applied to the data to determine whether it was possible to improve the distributions so that they satisfied the assumptions. Logarithmic and square root transformations were applied to the pre-test and post-test TSCC scores. The difference scores were also computed by subtracting the post-test from the pre-test scores. None of the transformations substantially improved the distributional properties, so in the interests of interpretability, it was decided to use the raw scores on the repeated measures MANOVA calculations. Only the extreme scores in Experimental Group 1 were dropped from the calculations. In fact, extreme outliers create a dilemma throughout this analysis. Clearly there were children in this study who were experiencing extreme difficulty and it is surmised that they were the subjects who were the outliers in the boxplots.

Figure 11.14: Boxplot of pre-test and post-test TSCC Total Scores:



11.7.1. Multivariate repeated measures ANOVA

Before proceeding with the full factorial MANOVA, it was decided to run a preliminary MANOVA that might assist with the problem of empty cells in the geographical region factor. The preliminary MANOVA requested only an analysis of first order interactions between the within subjects factor and the independent variables and covariate. The interaction between TSCC (pre-test/post-test) and Area was not significant (Pillai's Trace = .003; $F(2,584) = .91$; $p < .404$). This area factor was therefore excluded from further analysis, eliminating the problem of empty cells for the geographic area. The preliminary MANOVA also showed that the covariate, Adversity, was not significantly related to differences between the pre-test and post-test scores on the TSCC (Pillai's Trace = .001; $F(1,584) = .46$; $p < .499$). In the light of these preliminary

¹⁴ Howell (1997) suggests that, given reasonable cell sizes, ANOVA is robust under conditions where the largest cell size is 4 times larger than the smallest.

findings, a simplified Repeated Measures MANOVA was conducted using one within subjects measure (Pre-test and Post-test TSCC) and two between subjects independent variables: Condition (Experimental 1, Experimental 2, Experimental Group 3, Control 1 and Control 2) and Age group (younger, older).

Again heteroskedasticity was apparent. The Box test indicated that the covariance matrices were not equal ($p < .001$). However, since this test is considered to be overly sensitive (Hair et al, 1995), and since the univariate analysis suggested that the departure from assumptions was not severe, it was decided to proceed with the MANOVA, but to interpret the results cautiously using a stricter significance level of .02. Although this conservative approach would have the effect of decreasing power, it was believed that there was sufficient power in the design to identify even moderate effects for the two-way and three-way interactions. Table 11.13 reports the outcome of the multivariate tests, reporting only Pillai's Trace.

Table 11.13: Multivariate tests (Pillai's Trace) on the TSCC:

	Value	F	Hypothesis Df	Error	Sign.	Partial square	Observed power*
TSCC-Pre/post	.010	7.059 [#]	1.000	728.00	.008	.010	0.75
TSCC-pre/post x Condition	.098	19.676 [#]	4.00	728.00	.00	.098	1.000
TSCC pre/post x Age	.010	7.083 [#]	1.00	728.00	.008	.010	.750
TSCC pre/post x Condition x Age	.015	2.729 [#]	4.00	728.00	.028	.015	.750

Exact statistic

* Computed using alpha = 0.05

The results show that both of the two-way interactions are significant. The main effect for the within subjects factor is significant, but uninteresting given the higher order interactions. The three-way interaction is not significant by our conservative alpha level, but the results suggest that with more subjects, and hence a more powerful design, this small effect (see the Eta-value = 0.15) might have been significant. Levene's¹⁵ test of homogeneity of variance indicated that pre-test TSCC variances were equal ($p < .03$) but that the post-test variances were not ($p < .001$). Table 11.14 shows that two between-subjects main effects and the interaction were significant. These results indicated that the average of the pre-test and post-test TSCC scores differed for all groups, indicating both that the random assignment of subjects to experimental and control conditions did not result in equivalence, and also that the pattern of non-equivalence differed across the three areas.

¹⁵ Tests the null hypothesis that the error variance of the dependent variable is equal across the groups

Table 11.14: Between-subjects effects for TSCC scores

	Type III Sum of Squares	DF	MEAN SQUARE S	F	SIGN.	Part. Eta Square	Obs. Power*
Intercept	656.024	1	656.024	4841.911	.000	.869	1.000
Condition	4,904	4	1,226	9,049	0,000	0,047	0,999
Age	4,055	1	4,055	29,931	0,000	0,039	1,000
Condition X Age	1,921	3	0,480	3,545	0,007	0,019	0,869
Error	98.636	728	.135				

Transformed variable: Average

Computed using alpha = .05

11.7.3: Simple effects and groups differences

Howell (1997) suggests that lower order interactions are not interpreted when higher order interactions are significant. Instead simple effects should be conducted. Table 11.15 and Figure 11.16 show the simple effects for differences between the average TSCC scores for the 5 experimental and control conditions for the two age levels. As expected, both the younger and older subjects in Control Group 2 (non-vulnerable) score lower than the other groups. There was a general trend for older subjects to score higher than younger subjects, with this trend being most pronounced for Experimental Groups 2 and 3. Since Experimental Group 3 only had 48 subjects – whereas the other groups were comprised of roughly 180 subjects each – it is perhaps not surprising that random assignment did not result in equalisation. Although these between-subjects effects indicate non-equivalence of groups, since the within subjects MANOVA tests for *differences in the change in TSCC between groups*, this non-equivalence does not obscure the meaning of the within subjects effects reported above.

Table 11.15: Condition by Age allocation for the clinical symptom scores on the TSCC:

Condition	Age allocation	Mean	Std. Error	95% Confidence Level	
				Lower Bound	Upper Bound
Exp. 1	Younger	0,727	0,029	0,670	0,785
	Older	0,791	0,026	0,741	0,842
Exp. 2	Younger	0,615	0,029	0,595	0,707
	Older	0,877	0,029	0,820	0,935
Exp. 3	Younger	0,773	0,050	0,675	0,872
	Older	0,968	0,057	0,856	1,079
Control 1	Younger	0,745	0,027	0,693	0,797
	Older	0,816	0,028	0,761	0,871
Control 2	Younger	0,629	0,027	0,575	0,682
	Older	0,675	0,031	0,614	0,735

Figure 11.16: Trauma scores by Age and Condition

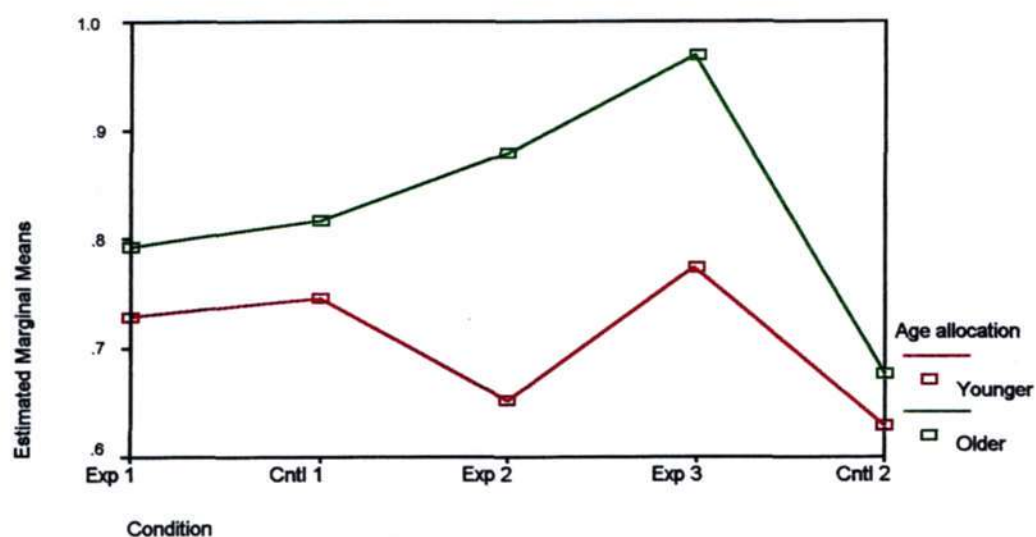


Table 11.16 and Figure 11.17 below help to explain the two-way interaction between TSCC pre- and post-test scores (i.e., the within-subjects factor), and the experimental and control conditions. There is a decrease in scores for Experimental Group 1 and for Experimental Group 2. These effects indicated that the interventions were significant, especially since there were no similar decreases in the two control conditions. However, the SGTP on its own was not an effective intervention as there were more clinical symptoms present for this group at the post-test than at the pre-test. This is consistent with literature that indicates that it is unacceptable to identify children on the basis of orphan status for an intervention, as this can create a sense of alienation and does little to develop cohesion within peer and community groups (Hunter & Williamson, 2002).

Table 11.16: Condition pre- and post-test for the trauma scores

Condition	Pre- /Post- test	Mean	Std. Error	95% Confidence Level	
				Lower Bound	Upper Bound
Exp. 1	Pre	0,857	0,026	0,806	0,908
	Post	0,662	0,026	0,611	0,713
Exp. 2	Pre	0,906	0,027	0,852	0,959
	Post	0,623	0,027	0,570	0,676
Exp. 3	Pre	0,794	0,051	0,695	0,894
	Post	0,947	0,051	0,848	1,046
Control 1	Pre	0,789	0,026	0,738	0,839
	Post	0,722	0,026	0,722	0,823
Control 2	Pre	0,610	0,027	0,556	0,664
	Post	0,694	0,027	0,640	0,748

Figure 11.17: Trauma scores by condition (pre- and post-test)

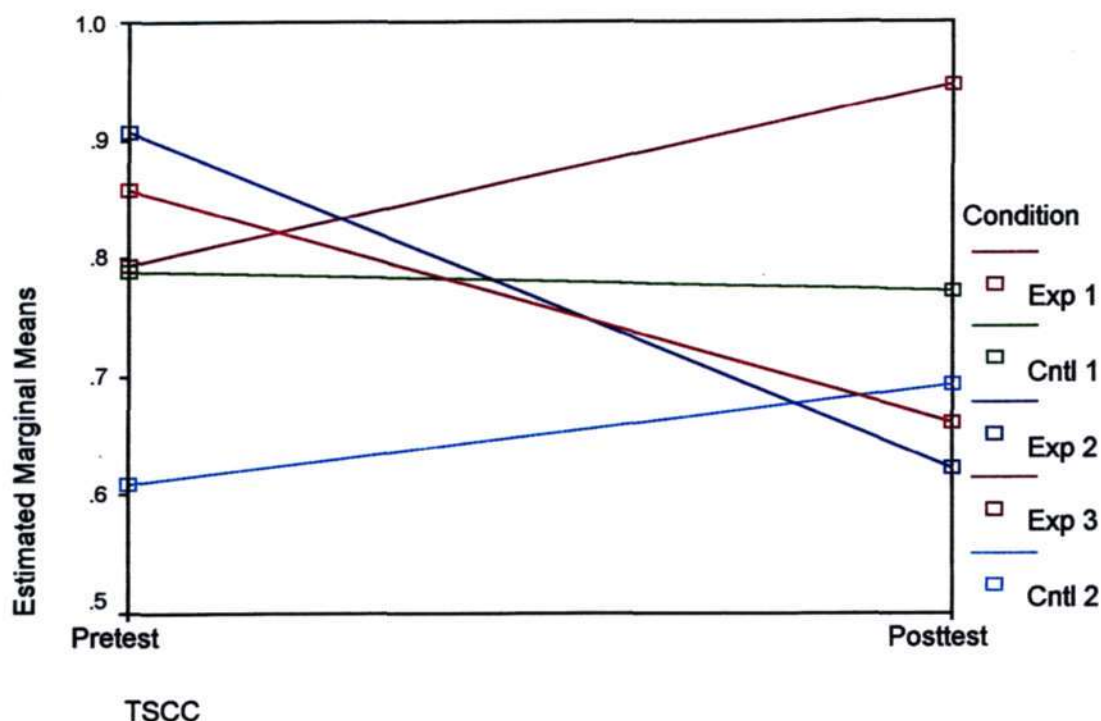


Table 11.17 and Figure 11.18 help to explain the two-way interaction between TSCC pre-test/post-test scores and Age. The results clearly show that there was an overall reduction in scores for the older but not the younger group, but this may reflect the fact that the children in Experimental Group 3, Control Group 1 and Control Group 2 showed no significant change across the pre- and post-test assessments.

Table 11.17: Age allocation by Pre and post test scores on the TSCC:

Age allocation	Pre/Post	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Younger	Pre	.705	.020	.666	.744
	Post	.705	.020	.666	.744
Older	Pre	.877	.021	.835	.919
	Post	.774	.021	.732	.816

Figure 11.18: TSCC Scores pre and post intervention showing the variance for age allocation:



11.8. Experimental effects for Social Support

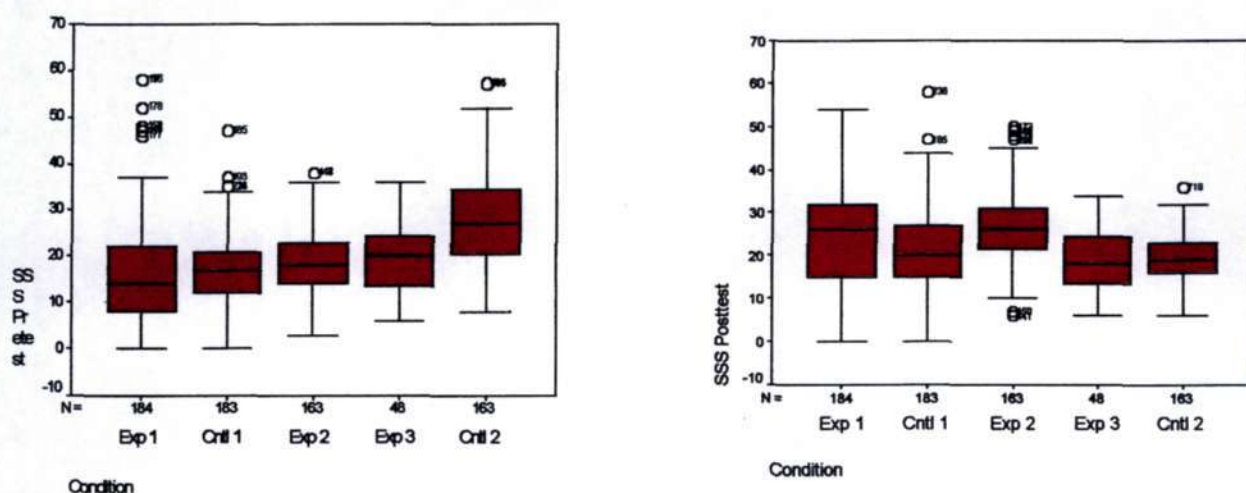
Multivariate analysis of variance, using the total summed scores for perceived access to social support (SSS-Access) was used to determine if the intervention increased SS when (1) the SGTP and SP were paired (Experimental Group 1), (2) SP intervention on it's own (Experimental Group 2), or (3) SGTP alone (Experimental group 3). The purpose was to see if the interventions had the effect of increasing the children's perceived access to SS. The initial design included one within-subjects factor – pre-test and post-test scores on SSS, and three between-subjects factors – Condition, Age group and Region, and the Adversity Index was used as a covariate. The main interest was again in the interaction between the within subjects SSS effect and Condition. A number of preliminary investigations were conducted. The results converged with those found on the depression and symptomatology scales indicating that the programme was effective.

11.8.1: Testing assumptions

The cell means and variances show that (1) the cell means differ substantially and do appear to be patterned across the independent variables and to increase from pre-test to post-test, (2) the condition of homogeneity of variance has not been met, but rather that variances differ substantially across cells – the problem is especially acute for the groups in the experimental condition, and (3) there is variation in the number of subjects per cell, there being no Township subjects in Control Group 2 and there are no Rural or Township subjects for Control Group 3 (Appendix R).

The boxplots in Figure 11.19 and histograms (not reproduced here) showed that the distributions for all conditions were roughly normal, although all the distributions were slightly positively skewed. The problem of heterogeneity of variance is apparent in the boxplots. A series of logarithmic and square root and reciprocal transformations were applied to the pre-test and post-test SSS-Access scores to determine whether it was possible to equalise the variances. None of the transformations substantially improved the distributional properties, so once again the raw scores were used on the repeated measures MANOVA calculations in the interests in maximising interpretability.

Figure 11.19: Boxplots indicating degree of variance for the SSS in the pre-test and the post-test.



11.8.2. Multivariate repeated measures ANOVA:

Due to the problem of there being empty cells in the Region factor, it was again decided to run a preliminary MANOVA requesting only an analysis of first order interactions for the within-subjects factor and the independent variables and covariate. The results of the multivariate tests are reported in Table 11.18. In this instance the covariate, Adversity Index, is related to the change in social support from the pre-test to post-test condition. The bivariate correlation between the Adversity Index and the Difference score calculated by subtracting post-test scores from pre-test scores was $-.125$ ($p < .002$). Reassuringly, this indicated that the higher the degree of adversity the child had experienced, the greater the increase in social support from pre-test to post-test. The results in Table 12.20 also show that the effect for Area was not significant. It was again decided to drop geographic region from the analysis because there was missing data for some of the Region conditions.

Table 11.18: Multivariate analysis within-subjects test for SSS-Access (Pillai's Trace):

Effect	Value	F	DF	Error DF	Sign.
SSS Pre/post	0,002	1,032*	1.000	634.000	0,310
SSS Pre/Post x Condition	0,273	59,556*	3.000	634.000	0,000
SSS Pre/Post x Region	0,004	1,299*	2.000	634.000	0,273
SSS Pre/Post x Age	0,017	10,784*	1.000	634.000	0,001
SSS Pre/Post x Adversity	0,011	6,826*	1.000	634.000	0,009

• Exact Statistic

In the light of these preliminary findings, a simplified Repeated Measures MANOVA was conducted using one within-subjects measure (pre-test and post-test SSS) and two between subjects independent variables: Condition (Experimental Group 1, Experimental Group 2, Experimental Group 3, Control Group 1 and Control Group 2) and Age Group (Younger, Older). Adversity was included as a covariate to determine whether the experimental intervention had an effect over and above the effect that adversity was generating in the perceived access to social support for the children. The within-subjects effects are reported in Table 11.19. Both the two-way interactions and the three-way interactions are significant. Only the Pillai's Trace results are presented.

Table 11.19: Multivariate tests for social support scores (Pillai's Trace):

Effect	Value	F	DF	Error DF	SIGN.	Partial Eta Square	Observed Power*
SSS Pre/post	0,000	0,172#	1.00	632	0,679	0,000	0,070
SS Pre/Post x Adversity	0,002	1,133#	1.00	632	0,288	0,002	0,186
SSS Pre/Post x Condition	0,277	60,443#	4.00	632	0,000	0,277	1,000
SSS Pre/post x Age	0,011	7,194#	1.00	632	0,008	0,011	0,764
SSS Pre/Post x Condition x Age	0,067	11,368#	4	632	0,000	0,067	1,000

Computed using alpha = .05

Exact statistic

Levene's test of homogeneity of variance confirmed the earlier observations that both the pre-test and post-test SSS-Access scores were heterogeneous across the groups. Table 11.20 shows that the main between-subject effect for Condition and the two-way interaction between Condition and Age were significant.

Table 11.20: Between-subject effects for social support scores

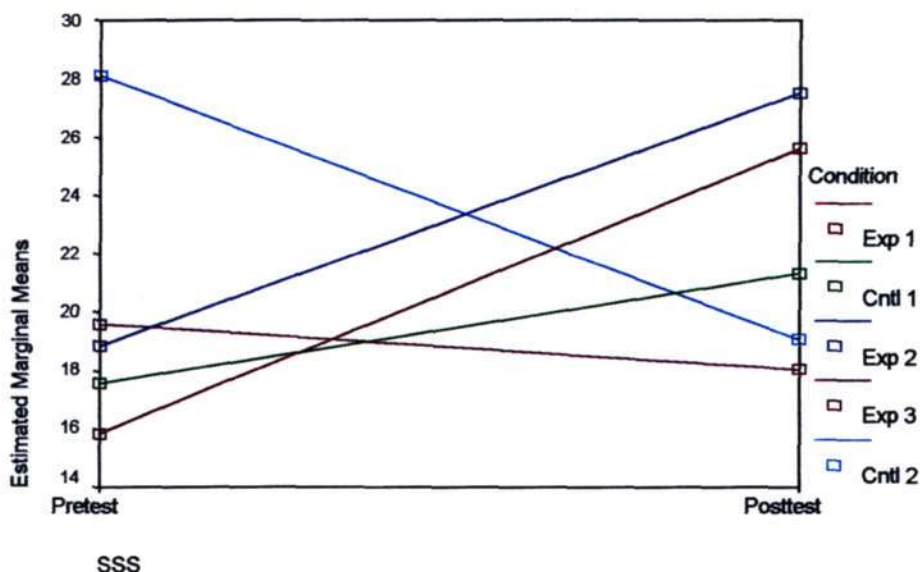
Source	Type III Sum of Squares	df	Mean Square	F	Sign.	Part. Eta Square	Observed Power*
Intercept	31038.445	1	31038.445	285.483	.000	.311	1.000
Adversity	101,994	1	101,994	0,938	0,333	0,001	0,162
Condition	3822,706	4	955,676	8,790	0,000	0,053	0,999
Age	289,897	1	289,509	2,666	0,103	0,004	0,371
Condition x Age	1874,038	4	468,509	4,309	0,002	0,027	0,931

* Computed using alpha = .05

11.8.3: Simple effects and groups differences

Although it is generally not advisable to interpret lower order interactions when the higher order interaction is significant (Howell, 1997), this summative evaluation had a special *a priori* interest in SSS by Condition for the within-subjects interaction. In addition, this effect was extremely strong in comparison with the others, so it will be scrutinised in detail together with the three-way interaction. Figure 11.20 and Table 12.21 show that there were significant, large increases in Access to SS for Experimental Groups 1 and 2, and more moderate (but nonetheless significant) increases in SS for Control Group 1. In contrast, there was a significant decrease in SSS scores for Control Group 4 and no change in SS for Experimental Group 3.

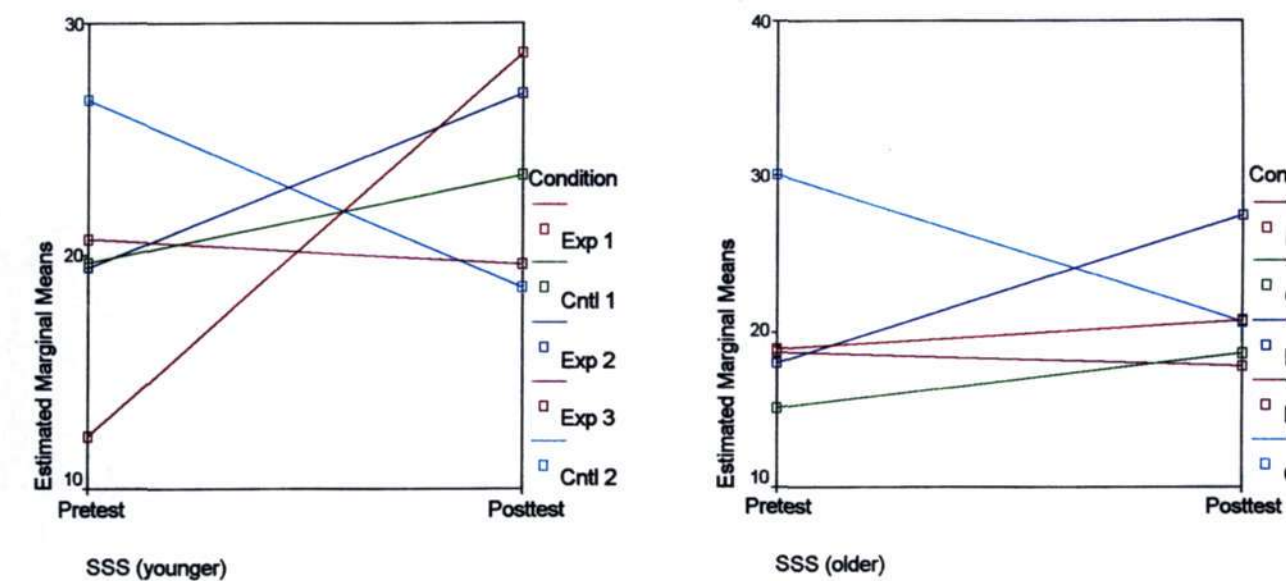
Figure 11.20: Social support scores by Condition (pre- and post-test)



Figures 11.14 and Table 11.23 show the pattern of cell means that make up the three-way interaction. They show that the significant increase in SS occurred only for the younger group (where there is a large effect size), but not for the older group. All the other patterns of mean

differences are much the same as those reflected in the two-way interaction between SSS and Condition discussed above.

Figure 11.14: The three interaction effects showing the effect on SSS-Access for the younger and older subjects:



Since the two-way interaction is significant for the between subjects effects, the main effects will not be interpreted (see Appendix S and Figure 11.21). They show the pattern of cell means of averaged pre-test and post-test scores that account for the interaction (Table 11.22). It is clear that there were differences in the group means for both the younger and older participants, but that the dispersion is higher for the older participants. Since Control Group 2 was a functional control, we expect social support to be higher for this group. The other differences between groups means indicates that the random assignment of subjects to experimental and control conditions did not result in rendering the groups comparable in terms of their perceived access to social support.

Figure 11.21: Social support scores by Condition and Age allocation

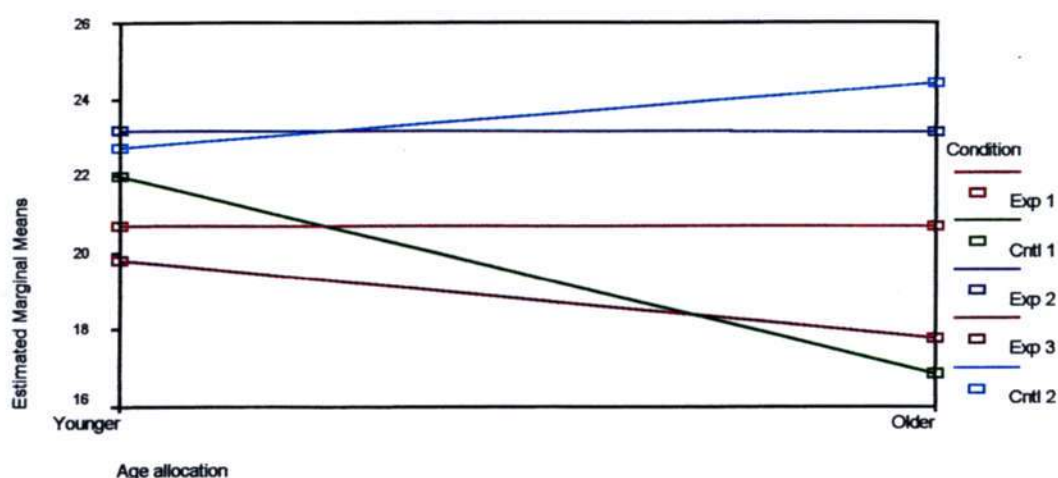


Table 11.21: Marginal means for social support scores by Condition and Age allocation

Condition	Age allocation	Mean	Std. Error	95% Confidence Level	
				Lower Bound	Upper Bound
Exp. 1	Younger	20,432	0,817	18,828	22,036
	Older	19,752	0,725	18,330	21,175
Exp. 2	Younger	23,205	0,807	21,620	24,790
	Older	22,731	0,822	21,117	24,346
Exp. 3	Younger	20,148	1,415	17,369	22,927
	Older	18,214	1,605	15,063	21,365
Control 1	Younger	21,547	0,751	20,073	23,021
	Older	16,793	0,789	15,245	18,341
Control 2	Younger	22,620	0,767	21,114	24,125
	Older	25,289	0,873	23,575	27,002

11.9. Experimental effects for Conners' Parent Questionnaires (Conners'):

Because of problems with the data, univariate factorial ANOVA was used to determine whether the intervention was effective in producing changes in the caregivers' evaluation of manifest symptoms. Difference scores were calculated by subtracting post-test scores from pre-test scores on the Conners'. ANOVA was used to determine which of three independent variables – Condition, Age group and Region – predicted change in the Conners' scores, after the effects of the covariate, Adversity, had been partialled out. The results were mixed, but indicated that the intervention was effective.

11.9.1: Testing assumptions

Of all the dependent variables that have been used to determine the efficacy of the interventions, the scores on the Conners' had the most problematic distributional properties. The histograms below (Figures 11.22) show that the distributions were anything but normal. Both were bimodal, and the pre-test scores were not symmetrical. Logarithmic and square root transformations did not substantially improve the distribution. However, the distribution of difference scores – post-test scores subtracted from pre-test scores – was roughly normally distributed (see Figure 11.23).

Figures 11.22: Histograms of Conners Parent's scores (pre- and post-test)

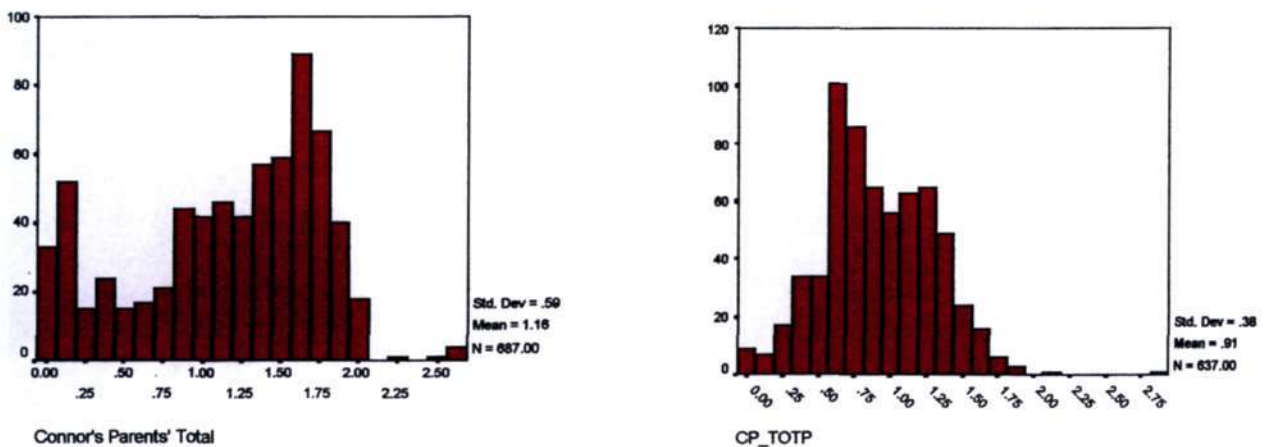
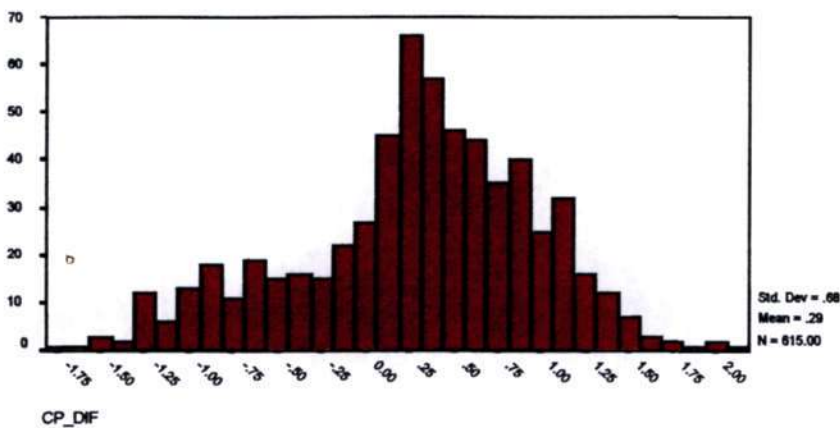


Figure 12.23: Histogram for Conners Parent's Difference scores



In addition to this lack of normality, the variance of the pre-test and post-test scores differed dramatically across the different Conditions. The variances of the Conners' difference scores for each of the Experimental and Control conditions is reported below in Table 11.23 and Figure 11.24. With the exception of Experimental Group 3, which has extremely low variance, the largest group variance is, acceptably, twice the size of the smallest. It appears as though the difference scores have both a more normal distribution and have greater homogeneity of variance than the raw scores. This is confirmed by the boxplots (Figure 11.25) for the difference scores for

each of the Experimental and Control conditions. With the exception of Experimental Group 3 – which had a reduced sample size ($n=48$), and for which there were only Peri-urban subjects – the distributions are symmetrical and of similar variance. It was thus decided to use difference scores rather than the raw scores for the inferential tests. Because of the problems with Experimental Group 3 it was dropped from analysis.

Figure 11.25: Boxplot for Conners' Parent's scores

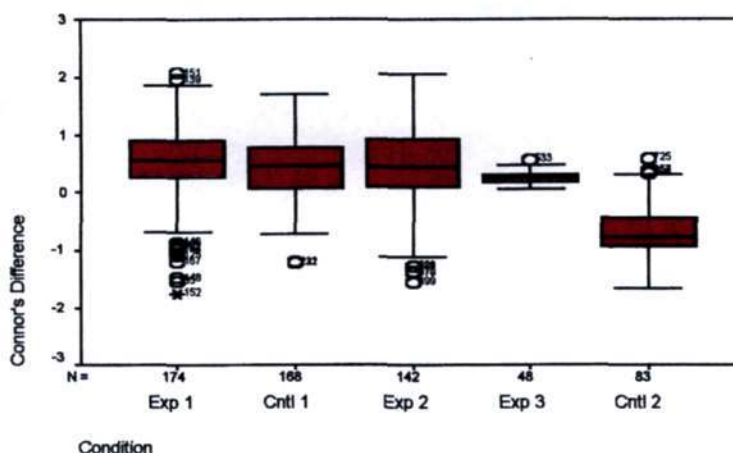


Table 11.23: Conners' difference scores by Condition, Region and Age:

Pre-test		Age allocation							
Condition	Region	Younger				Older			
		N	Mean	Std. Dev	Var.	N	Mean	Std. Dev	Var.
Experimental Group 1	Rural	21	0,58	0,77	0,59	28	0,18	0,75	,542
	Peri-urban	37	0,67	0,42	0,18	45	0,41	0,64	,421
	Township	23	0,80	0,51	0,26	30	0,45	0,67	,411
Experimental Group 2	Rural	42	0,77	0,62	0,39	37	0,12	0,63	,436
	Peri-urban Township	41	0,77	0,61	0,38	43	0,11	0,45	,248
Experimental Group 3	Rural	27	0,25	0,10	0,01	21	0,27	0,12	,032
Control Group 1	Rural	25	0,37	0,44	0,19	24	0,76	0,24	,014
	Peri-urban	45	0,14	0,46	0,22	37	0,50	0,56	,312
	Township	26	0,44	0,57	0,32	26	0,62	0,43	,165
Control Group 2	Rural	27	-,16	0,34	0,12	17	0,60	-	
	Peri-urban	38	-,86	0,23	0,05	32	0,09	-	
	Township	27	-,83	0,40	0,16	22	-	-	

Unfortunately, there were still further problems with the data, which can be detected from the descriptive statistics in Table 12.24. The majority of parent/primary caregiver respondents from Control Group 2 (non-vulnerable) did not complete the post-test and therefore difference scores

could not be computed for these subjects. All except two of the scores were missing for the older subjects in Control Group 2. Because of these empty cells it would not be possible to properly perform cross factors to investigate interactions. Thus, it was decided that only main effects, in this instance, would be tested in the ANOVA.

11.9.2: Univariate ANOVA

A univariate ANOVA was conducted to determine whether the mean difference between pre-test and post-test scores varied across the groups. Because of problems with heterogeneity of variance, Experimental Group 3 was excluded from the analysis. In addition, because of the remaining empty cells it was decided to test a custom model, including only the main effects – Condition, Age group, and Region. Because of design problems, the main effects would distort the interaction effects rendering them essentially uninterpretable. Adversity was included as a covariate, to determine whether change in parent ratings was due the experimental factors (main effects) over and above the levels of adversity experienced by children. Levene's test indicated that the variances differed across the cells ($F(20,544) = 2,339, p < .001$). Although this was already known, the F value is not very large, suggesting that the analysis would be robust, despite the heterogeneity of variance.

Table 11.25: Between subjects effects for Conners' difference scores

	Type III Sum of Squares	DF	Mean Square	F	Sign.	Part. Eta Square	Observed Power#
Corrected model	109,056*	7	15,579	65,469	,000	,470	1,000
Intercept	,008	1	,008	.,33	,855	,000	,054
Condition	92,429	3	30,810	129,471	,000	,429	1,000
Age	2,072	1	2,072	8,708	,003	,017	0,838
Region	2,149	2	1,075	4,516	,011	,017	0,770
Adversity	2,903	1	2,903	12,201	,001	,023	0,937
Error	122,791	516	.238				
Total	297,730	524					
Corrected Total	231,846	523					

Computed using alpha = ,05

* R Squared = ,470 (Adjusted R squared = ,463)

The between subjects effects are reported in Table 11.26. All three main effects plus the covariate are significant at the level $\alpha = .02$. Adversity was positively correlated with the difference scores ($r = .20, p < .0001$), indicating that children with higher adversity were rated by their primary caregivers as more improved – i.e., they had a greater drop in post-test scores relative to pre-test scores – than children with lower levels of adversity. The effect size shows that the effect for Condition was by far the most important of the three main effects. The non-significant intercept

indicated that overall, the grand mean of the difference scores was not significantly different from zero.

11.9.3: Simple effects and groups differences

Much caution was exercised in the analysis above, to determine whether the main effects were significant or not. Since the effect for Condition was significant and has a substantial effect size, a more liberal approach was taken in investigating the pattern of group mean differences. Specifically, to gain an overall picture of group mean differences, Experimental Group 3 was included in the descriptive statistics. The histogram shows that the mean for the Experimental Group 1, 2 and 3 and for Control Group 1 was positive whereas the mean for Control Group 2 was negative. This indicates that the mean post-test scores were lower than the mean pre-test scores for the all groups except Control Group 2, whose subjects were given higher scores in the post-test than on the pre-test. Pairwise comparisons were conducted to identify the pattern of significant means differences. Table 11.27 shows that Experimental Group 1 differed from Control Group 2, but that Control Group 1 and Experimental Group 2 were not significantly different (see Figure 11.28). Experimental Group 3 was not included in the pairwise comparisons since its low variance would make the tests too liberal. Nonetheless, the bar graph suggests that the mean score for Experimental Group 3 is substantially less than that for Control Group 1, and it thus significantly lower than that of the experimental effect. A word of caution is in order here. Since there were sampling problems with Experimental Group 3 and Control Group 2, and since there were high levels of non-random subject mortality for Control Group 2, these findings are merely suggestive.

Table 11.28 shows that the younger group had greater mean difference scores than the older group, indicating that there was a greater reduction in post-test score relative to pre-test score for this younger group.

Figure 11.25: Connors Parent's scores Condition means

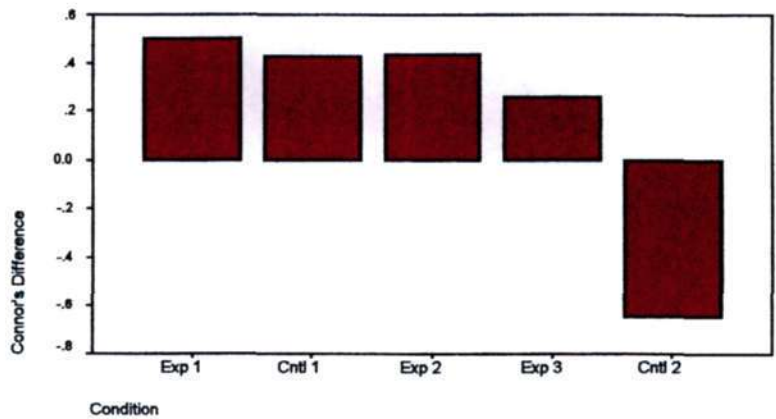


Table 12.27: Pairwise Comparisons for Conners' difference scores by Condition

Condition 1	Condition 2	Mean Diff.	Std. Error	Sign.*	95% Confidence Level#	
					Lower Bound	Upper Bound
Experimental Group 1	Control 1	0,155*	0,057	0,040	0,004	0,305
	Exp. 2	0,146	0,061	0,100	-,015	0,307
	Control 2	1,338*	0,072	0,000	1,147	1,530
Experimental Group 2	Exp. 1	-,146	0,061	0,100	-,307	0,015
	Control 1	0,009	0,060	1,000	-,151	0,169
	Control 2	1,192*	0,074	0,000	0,996	1,389
Control Group 1	Exp. 1	-,155*	0,057	0,040	-,305	-,004
	Exp. 2	-,009	0,060	1,000	-,169	0,151
	Control 2	1,184*	0,070	0,000	0,999	1,368
Control Group 2	Exp.1	-1,338*	0,072	0,000	-1,530	-1,147
	Control 1	-1,184*	0,070	0,000	-1,368	-,999
	Exp. 2	-1,192*	0,074	0,000	-1,389	-,996

Based on estimated marginal means

* The mean difference is significant at the ,05 level.

Adjustment for multiple comparisons: Bonferroni.

Table 12.28: Conners Parent's difference scores by Age allocation:

Age allocation	Mean	Std. Error	95% Confidence Level	
			Lower Bound	Upper Bound
Younger	0,315*	0,030	0,257	0,374
Older	0,178	0,037	0,105	0,250

• Adversity Index Covariate, used in the model are evaluated 16,3664.

The pairwise comparisons reported in Table 11.29 show that the rural group had significantly higher scores than the township group, and that the mean for the peri-urban group fell between these and was not significantly different from either.

Table 11.29: Pairwise comparisons for Conners' difference scores by Region:

Region 1	Region 2	Mean Diff.	Std. Error	Sign.	95% Confidence Level	
					Lower Bound	Upper Bound
Rural	Peri-urban	0,145	0,050	,012	0,025	0,266
	Township	0,051	0,063	1,000	-,101	0,204
Peri-urban	Rural	-,145	0,050	0,012	-,266	-,025
	Township	-,094	0,057	0,302	-,231	0,043
Township	Rural	-,051	0,063	1,000	-,204	0,101
	Peri-urban	0,094	0,057	0,302	-,043	0,231

Based on estimated marginal means

* The mean difference is significant at the ,05 level.

Adjustment for multiple comparisons: Bonferroni

It is clear from the Conners' results that there was an overall improvement in the children in the different Conditions as rated by the caregivers, with those children with higher Adversity scores

in pre-testing being rated as being most improved (by their caregivers) in post-testing. This would suggest that the SP had been effective in sensitising the community members, and possibly the caregivers, to the psychosocial risks factors to which the children had been exposed.

11.10: Use of western psychometric instruments in the current context

Using western-standardised psychometric instruments was highly ambitious. The desire had been to subject the SGTP to comprehensive and thorough evaluation for various reasons: (i) It is essential that we know which programmes benefit which children under which conditions and how the effect operates. PSS is a concept that has a long tradition (it essentially incorporates good child rearing practices over the ages) and a short formal past. PSS remains a difficult concept to define accurately. It is difficult to know if the minimal standards are being met and if one is achieving the objective of the intervention. (ii) Human and financial resources are being severely stretched by the HIV/AIDS pandemic, so one needs to be know if a programme is effective, and for whom it is effective. We cannot afford to pour resources into activities that do not achieve their objectives.

It had been decided to try to use western derived tests to measure the effect of the programme. In turn, this necessitated an extremely cautious approach to the statistical analysis of the data. Each of the measures needed to be evaluated for internal reliability, for time consistency and validity. It was interesting and distressing to note that the only test that did not meet the requisite criteria for reliability was the CFSEI (Battle, 1992). It was distressing since the researcher had hoped that the increase in self-esteem would be the major indicator of the effectiveness of the programme. In fact, the researcher was rather surprised to find that she had clear preconceived ideas about self-esteem being a critical foundation upon which resilience is built. This may still be the case. However, there is no evidence to support or refute this preconception. Anecdotal information from the apprentice facilitators, however suggests that the concept of self-esteem has little meaning in collectivist African cultures. The concept of evaluating self without valuing and acknowledging the critical role of others is contrary to their cosmology and to the concept of *Ubuntu* (Mkhize, 2004). This is an area for further empirical investigation, as self-esteem needs to be understood and measured in a completely different manner within collectivist cultures.

The acceptable levels of Cronbach Alpha in the other dependent variables allowed the researcher to proceed with caution. Several decisions had to be made about how best to proceed in a defensible manner. The correlation matrices revealed that although there was redundancy of data within the measures, the correlations were relatively weak, though significant, especially across

the pre and post intervention assessments. It was thus necessary to introduce a degree of stringency by setting conservative alpha levels of 0,02 (Hair et al., 1990). Problems of heteroskedacity remained, with the most troubling problem being the lack of pre intervention equivalence between the experimental and control groups. The researcher is unable to explain why there was no pre-intervention equivalence, as one could have reasonably assumed from the procedures that had been adopted that one would obtain parity before implementing the interventions. One can only hope that this reflects the difficulties that are experienced in real world research in which it is impossible to control for all confounding variables (Robson, 2003), and it became necessary to use more robust forms of statistical analysis.

11.11. General pattern of results across the various dependent variables:

The results demonstrate the need for both a community and child level of intervention, since the greatest improvement in terms of alleviating symptoms and building resilience was found amongst the children who formed Experimental Group 1 and Experimental Group 2. It seemed that the children needed the benefit from the attention and support offered under thee conditions. On the other hand, Experimental Group 3 whilst benefiting from the opportunity to express their feelings, did not have resilience built in terms of establishing greater integration within their communities. The subscale changes within the TSCC showed raised scores on the anxiety, posttraumatic stress, anger and sexual concern subscales, while there were significant decreases on the depression and dissociation subscales.

The most detrimentally affected children were the non-vulnerable children who were excluded from the intervention programmes (even though it was discovered that some had been attending the community-based initiatives). This is a disturbing result as it suggests that any form of exclusionary criteria could be detrimental to at least some children. The process of targeting certain children for intervention leaves some children feeling excluded and they subsequently report an increase in symptoms of distress. An important factor to bear in mind in this regard is the extreme poverty that was encountered in all of the partnering communities, such that there were few (if any) extra-mural, faith-based or cultural activities for children. Therefore, the highly unusual and very apparent occurrence of people driving into an area to play/work with certain children had a negative effect on those children who were not included. The non-vulnerable children seemed to have been the ones who were most likely to have been active participants in other forms of activity and therefore their exclusion were probably felt more acutely. They had been used to being the children whom were usually chosen to play sports (if sporting activities were available), to perform in choirs, to run errands at school, etc. As the intervention represented

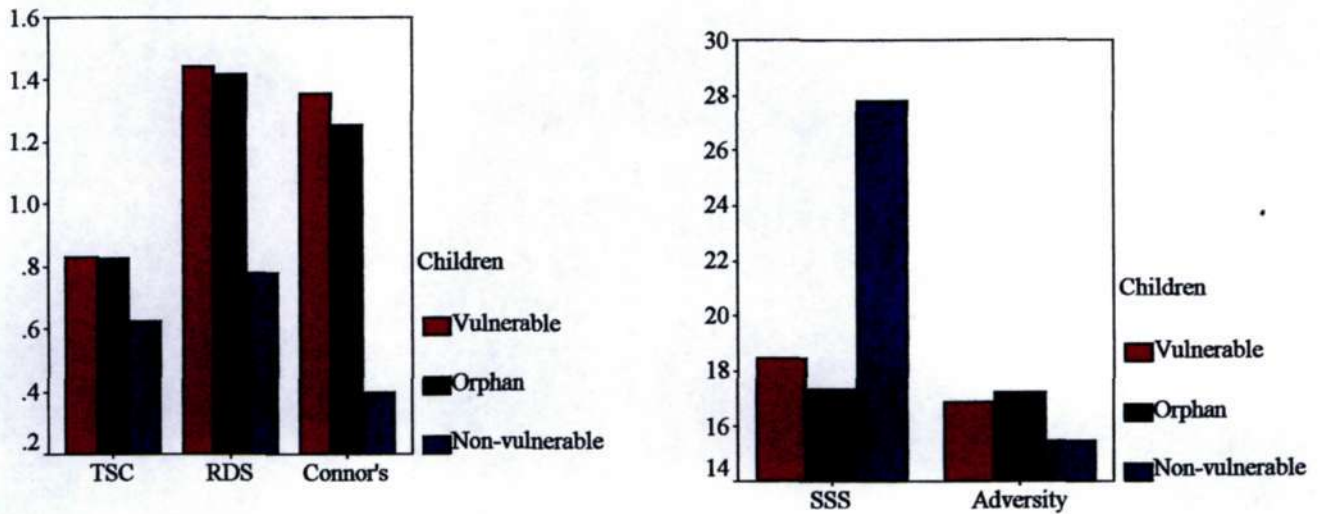
a strong deviation from this normal pattern, the non-vulnerable children felt left out and were unhappy about this. This raises the question of how one can, in a resource limited context, avoid perpetuating a 'lucky orphan' scenario, in which all children are encouraged to participate. It also indicates that psychosocial interventions need to be targeted at the community level, with the objective of building community cohesion and compassion.

It was interesting to note that the Adversity Index and Death Experience measure did not correlate strongly with depression scores. The literature indicates that one would expect a strong correlation (Bowlby, 1988; Brown & Lourie, 2000; Christ, 2002; Garnezy, 1986; Masten, 2002) between the number of recent close deaths and depressive symptoms. Given that both of these measures indicated the extreme psychosocial risks to which the children had been exposed, this may suggest that children who experience a multitude of deaths and other adversities respond differently to children who experience death as an occasional occurrence within their environment. The researcher is not familiar with theories or empirical studies that investigate the emotional, social and behavioural impact of multiple deaths, even in the fields pertaining to children who live in situations of armed conflict. This is clearly an area that needs empirical and theoretical investigation. Some writers, for example, Schönteich (2002) have made dire prediction about the security of the entire civil society if generations of children are raised without nurture and secure attachments. Germann and Madörin (2002) partially endorse this pessimistic view, choosing to rather focus on the urgent need to offer PSS. However, unless mental health professionals understand the impact of multiple deaths within a family and community on children, it is difficult to develop effective programmes. Germann and Madörin (2002) theorise that multiple deaths could be associated with many different emotional responses, only one of which could be depression. In fact, Madörin (2000b) stated that anger, self-blame and anxiety are the more likely emotional consequences of multiple death and adversity.

11.12: Psychosocial Profiles of vulnerable verse non-vulnerable children:

Although the following section deviates from the main thrust of this research, it is considered to be important to use the data to inform some of the prolific debate about the nature of vulnerability and its impact on children. There was much similarity in the psychosocial profiles of the vulnerable children, with little difference found between those children rendered vulnerable due to having been orphaned and those who were vulnerable due to other circumstances.

Figure 11.26: Group means for the three categories of children across the five variables:



Using only their pre-test scores, five separate one-way ANOVAs were conducted to determine whether the two categories of children (vulnerable due to being orphaned or not, and non-vulnerable) scored differently on the TSCC, RDSC, SSS, the Adversity Index, and the Conners' Parent Questionnaire. The results in Table 11.26 show that all effects were significant. The strongest effect was on the Conners' ($\eta^2 = .32$), followed by RDSC ($\eta^2 = .27$), SSS ($\eta^2 = .19$), TSCC ($\eta^2 = .05$) and Adversity Index ($\eta^2 = .015$). It is noteworthy that the effect sizes are large, indicating substantial differences between the groups.

Table 11.28: ANOVA Results for the vulnerable and non-vulnerable children by the four dependent variables:

	Sum Square	df	Mean	F	Sign.
TSCC – Total					
Between	5.81	2	2.90	22.11	.00
Within	96.77	736	.13		
Total	102.58	738			
RDSC – Total					
Between	55.56	2	27.78	134.54	.00
Within	151.98	736	.20		
Total	207.55	738			
SS Access– Total					
Between	14528.84	2	7264.42	84.14	.00
Within	63715.83	738	86.33		
Total	78244.68	740			
Adversity – Total					
Between	248.65	2	124.32	3.87	.00
Within	16326.04	640	25.50		
Total	16574.70	642			
Connors'– Total					
Between	78.67	2	39.33	163.99	.00
Within	164.07	684	.24		
Total	242.75	686			

Figure 11.27 shows how the group means differ for each of the five variables. They show major differences between the vulnerable children and orphans on the one hand and non-vulnerable children on the other.

Post hoc tests were conducted to provide a more exact picture of the pattern of differences between the group means. Levene's tests showed that the variances across the groups were not equal for RDSC, SSS, Adversity Index and Connors', but were equal for TSCC. Thus Tukey's HSD test was used to compare the group means for TSCC and Dunnett's T3 test was used for the variables where the homogeneity of variance assumption did not hold. The results showed that in all instances the vulnerable group and the orphans differed significantly from the non-vulnerable group (Table 14.2). The tests showed that the means of the vulnerable group and orphans did not differ significantly on TSCC, RDSC, SSS, and Adversity Index, but did differ on the Connors' measure, where the vulnerable children in fact had a higher mean than the orphans. Although these effect sizes give an indication of the 'importance' of the individual variables in distinguishing between the three groups, the variables are intercorrelated (see Table 11.30), and so these effect sizes may provide a misleading picture of the importance of each of the variables in jointly predicting group differences.

Table 11.29: Descriptive statistics for the three categories of children:

	Children					
	Vulnerable		Orphans		Non-vulnerable	
	Mean	Std. Dev.	Mean	Std. Dev.	Mean	Std. Dev.
TSCC- Total	,83	,36	,83	,38	,61	,34
RDSC	1,45	,45	1,43	,49	,75	,37
SSS- Access	18.18	9.40	17.24	8.20	28.76	11.16
Adversity Index	16,91	5,17	17,24	5,41	15,49	3,62
Connors'	1,36	,51	1,25	,52	,40	,32

Table 11.30: Correlation matrix showing pre- and post-scores for each of the tests:

		TSCC	RDSC	SSS	Adversity	Connors'
TSCC	Pearson Correlation	1	,413**	-,210**	-,026	,129**
	Sig. (2-tailed)		,000	,000	,504	,001
	N	739	737	739	641	685
RDSC	Pearson Correlation	,413**	1	-,298**	,192**	,382**
	Sig. (2-tailed)	,000		,000	,000	,000
	N	737	739	739	643	687
SSS	Pearson Correlation	-,210**	-,298**	1	-,059	-,222**
	Sig. (2-tailed)	,000	,000		,137	,000
	N	739	739	741	643	687
Adversity	Pearson Correlation	-,026	,192**	-,059	1	,270**
	Sig. (2-tailed)	,504	,000	,137		,000
	N	641	643	643	643	643
Connors'	Pearson Correlation	,129**	,382**	-,222**	,270**	1
	Sig. (2-tailed)	,001	,000	,000	,000	
	N	685	687	687	643	687

** Correlation is significant at the 0,01 level (2-tailed)

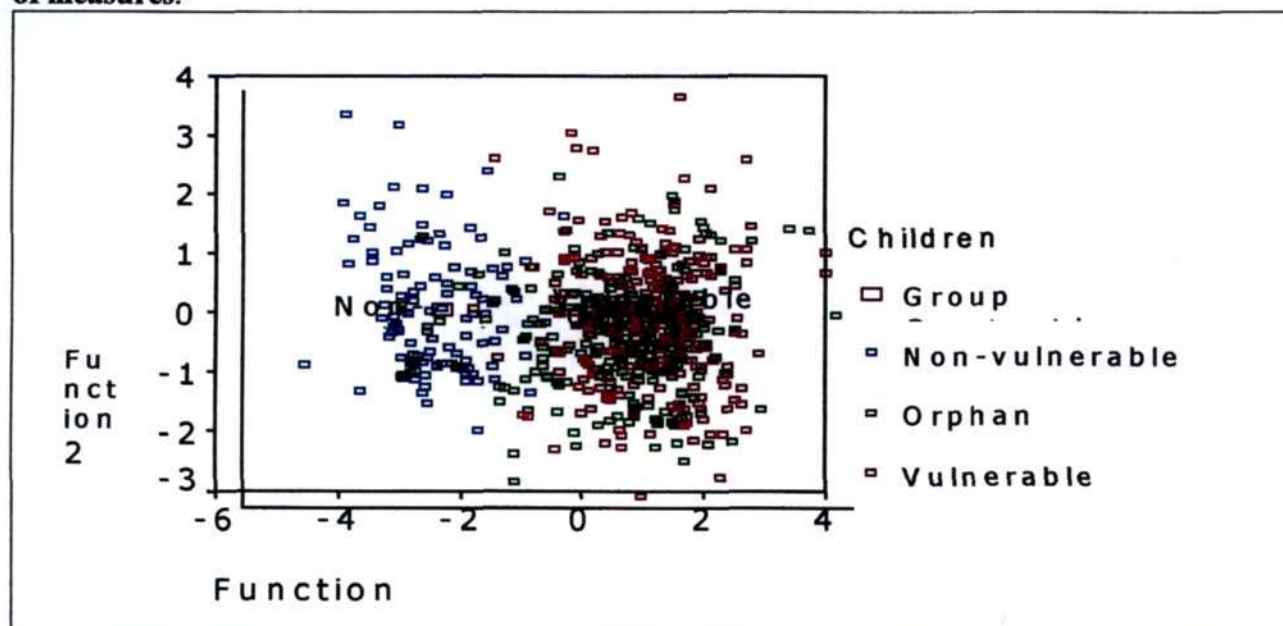
Multiple discriminant analysis was conducted to determine (1) the importance of each of the variables in a joint prediction of group membership, and (2) power of the set of variables as a whole to discriminate between membership. An empirically-driven stepwise approach was taken to developing an overall model. The final model excluded the TSCC, but included the other four variables. Two canonical discriminant functions were identified by this procedure (See Table 14.4). The first had a canonical correlation of .73 with the groups, while the second was much less useful in discriminating between the groups having a canonical correlation of .13. The table shows that Function 1 was made up largely from scores on the Conners' measure, followed by RDSC and SSS. Function 2 consisted largely of data from the SSS and the Adversity Index, although the Conners' was useful here too.

Table 14.4: Standardised canonical discriminant function coefficients:

	Function	
	1	2
RDSC	,339	-,168
SSS	-,308	,803
Adversity Index	-,168	-,458
Conner's Parent Questionnaire	,837	,502

The plot shows that the first function clearly distinguishes the non-vulnerable children from the vulnerable children and orphans (Figure 11.27). The lack of overlap between these groups indicates how well the combination of variables making up factor 1 work to distinguish the subjects, and explains the high canonical correlation of .73.

Figure 11.27: Canonical discriminant function by category of children and a combination of measures.



These findings have implications for targeting interventions only for orphans, since it is clear that the psychosocial profile of distress is very similar across different forms of vulnerability. It also support the literature that was surveyed in Chapter 3 of this dissertation that proposes that children walk the long road of distress which begins long before the death of a parent.

Chi-square tests indicate that the differences between the three categories of children were significant across the three groups (See Table 11.29).

Table 11.29: Chi-square tests results by form of spontaneously mentioned adversity and category of subject:

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-square	48.840(a)	4	.000
Likelihood ratio	51.993	4	.000
Linear-by-Linear Association	20.765	1	.000
N of Valid Cases	641		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 30.30.

From the above canonical analysis it would seem that vulnerable children – be they orphans or have experienced other forms of adversity display similar types of psychopathology. Therefore it seems that hypothesis 1 is confirmed in the null form: orphaned children do not exhibit substantially different profiles of distress to children rendered vulnerable by other circumstances. The international thrust (Hunter & Williamson, 2002; UNICEF, 2002) towards considering orphans and vulnerable children as being in similar need of special consideration is therefore supported by this data. It seemed therefore that community members were able to distinguish between vulnerable and non-vulnerable children, and that there were differences in the form of adversities experienced by children rendered vulnerable by virtue of their being orphans and those who were vulnerable due to other factors. The overlap between vulnerable children and orphans in terms of the psychometric measures suggests that despite different adversities, the impact on children is similar. Of particular interest were the seventeen orphaned children who were identified as non-vulnerable. Clinical consideration of their psychometric profiles suggests that their categorisation into the non-vulnerable group was valid.

There was support for the findings of various authors who have noted that vulnerable children are more likely to manifest internalising disorders as opposed to externalising disorders (Brown & Lourie, 2000; Flemming et al., 1997). This means that they are less likely to be identified as

'problem children' since they are less disruptive in classroom and other situations. In turn, this may mean that they are less likely to access help.

11.10: Summary of results:

In general the results show that the SGTP, especially when paired with the SP is an effective intervention strategy in that it alleviates symptoms and leads to an increase in perceived access to social support. The SGTP in general was evaluated as being effective in decreasing depression and other symptoms of distress and increasing perceived access to social support. However, the quantitative evaluation in the positivist tradition was fraught with potential problems, most of which seem to have been relatively successfully overcome.

It must first be mentioned that certain aspects of the research questions could not be answered. The programme was not successful in the two informal settlements as children were not a priority for these groups of people who face different problems that require their more urgent attention. Secondly, the educators were less than co-operative, leading to high subject mortality in terms of the response rate for the Conners' Teacher Questionnaires. Thus, these had to be dropped from the analysis. Cautious exploration of all of the psychometric measures of the dependent variables led to the CFSEI also being dropped, as it did not meet the requisite standards for reliability.

The general pattern of results, as presented in Table 11.30, shows the areas of general improvement that occurred within-subjects across the pre- and post-test assessments. Improvement is defined as a decrease in reported symptomatology or an increase in perceived access to social support. Detrimental effect is defined as an increase in reported symptoms or less perceived access to social support. This table of results shows that children who were in Experimental Group 1 improved in terms of all of the dependent variables and thus it can be concluded that the most effective intervention programme in terms of this research is the combination of the SP and the SGTP or the SP on its own, dependent on the SP being a preceding PSS activities within the community. In contrast, the other experimental and control conditions, were less effective in bringing about positive change in all spheres of functioning as measured in this research programme.

Table 11.30: General pattern of results across the various dependent variables:

	Experimental Group 1	Experimental Group 2	Experimental Group 3	Control Group 1	Control Group 2
Brief Description	SP + SGTP	SP only	SGTP only	Alternate programme	Non-vulnerable No intervention
RDSS (Figure 11.13)	Improved	Improved	Improved	No sig. Change	Detrimental effect
TSCC (Figure 11.17)	Improved	Improved	No sig. change	No sig. Change	No sig change
SSS (Figure 11.21)	Improved	Improved	No sig. change	Improved	Detrimental effect
Conner's (Figure 11.28)	Improved	Improved	Improved	Improved	Detrimental effect

Experimental Group 2 (SP and community based initiatives only, no SGTP) seems to have been an effective form of intervention in as much as it led to improvements in perceived access to social support and less symptoms being reported by both the children themselves and their parents/primary caregivers. It therefore is reasonable to assume that although participation in regular PSS activities organised by adult members of ones' own community are beneficial in reducing emotional and behavioural symptoms and increasing perceived access to social support, it is more beneficial to give children the opportunity to directly speak about their hardships and to have activities that prepare them for a positive cognitive framing of their life experiences. This is consistent with views that therapeutic interventions are more effective than participation in, for example, social skills training courses (Kazdin, 2000). The vulnerable children in this research programme benefited more from participation in the SGTP compared with children who only participated in a range of community based PSS initiatives, even though both forms of intervention led to improved overall functioning in the children. However, it was not possible to obtain accurate records of the attendance, nature and duration of the various PSS activities that were attended by individual children in Experimental Conditions 1 and 2.

Experimental Group 3 children were selected on a different basis to the other children who participated in the rest of this research programme. They were identified on the basis of their orphan status and they were only offered the SGTP, with no related community intervention. The therapeutic effect of the SGTP is evident in the decreased levels of depression and self-reported and primary caregiver-reported symptoms, but there was no significant change in their ability to access social support nor in the range of symptoms that were identified using the TSCC, which as a total symptom score, showed no significant change. The SGTP therefore on its own, without any concomitant intervention at the community level can thus only be considered to effectively reduce depression and the symptoms measured on the Conner's Parent/Primary Caregiver

Questionnaire. It also did not lead to a significant increase in perceived access to social support and thus is it theorised that this aspect of resilience-enhancement was not improved.

The effect of the intervention for Control Group 1 is difficult to explain. They participated in the same number of sessions, with similar adult:child ratios and nutritional input in the form of snacks and refreshments, as those children who formed Experimental Group 1. It seems that even though their parents/primary caregivers report a reduction in symptoms the children do not self report reduced symptoms, perhaps as they have not directly addressed their symptoms. Vulnerable children from the partnering communities had been randomly assigned to the either Experimental Group 1 or Control Group 1, so it is also difficult to explain the pre-intervention non-equivalence between these two groups. Nevertheless, the effect of the intervention with them (alternate programme, plus SP and community based PSS activities) is to be seen in no reduction in self reported symptoms, but a reduction in symptoms reported by their parents/primary caregivers and in their perceived access to social support.

These results indicate that the Experimental conditions had an overall positive effect on the children, but that the nature of the effect differs with different intervention programme combinations. The community-based intervention programme that consists of all the phases from community mobilisation, to the SP, to the SGTP and the community-based initiatives was shown to be the most effective form of intervention. Although having some benefits, one does not obtain maximum benefit for the children when one offers them only isolated aspects of the holistic programme. These results will be discussed in greater depth in the following sub-section.

Section VI

Drawing it altogether

Chapter 12:

Discussion of the results of the overall programme

This chapter discusses the major results and considers the limitations of the study and the implications for further research, practice and policy formulation. The dilemmas faced by the researcher as she juxtaposed the roles of scientific researcher, advocate for children and programmatic implementer at a community level will also be discussed. The researcher defines herself primarily as an activist: someone who works within the community with the objective of development and empowerment of people who have been unfairly prejudiced by their life circumstances. She has seen herself as being a relatively privileged member of society in terms of being better able to access resources. Being a researcher required a different life position. The tension that emanated from these roles was a major motivator in conducting this research, since it was believed that by meshing the roles of researcher, advocate and implementer she would be able to make a meaningful contribution to the lives of vulnerable children. It was also this tension that contributed towards the adoption of particular methodologies and research design. However, the mere act of trying to combine these roles proved to be challenging. The primary objective of all reasonable research is to suspend judgements and to let the research question dictate the process and the outcome. The fact that the researcher was also one of the people who had developed the programmes that were to be evaluated required special attention in terms of objectivity and reliance on what the data was actually presenting, as opposed to the way in which the data was being read and interpreted. The ways in which the researcher reflected and acted on these roles will be discussed in this chapter.

12.1. General pattern of results:

In general, this community-based programme has been shown to effectively offer psychosocial support to vulnerable children, especially when attention is given to both the community and child levels of intervention. Working within nine communities in the KwaZulu-Natal province of South Africa, there are four elements that are believed to have been of critical importance in ensuring the success of this programme. These general patterns are discussed, before attention is given to the finer details of the results.

Firstly, the establishment of strong collaborative partnerships within the communities created a sense of this being a shared endeavour that was of mutual benefit to the partnering communities and to the

researcher. Genuine power sharing and joint decision-making had to be a primary objective, especially since empowerment of the communities was an ultimate goal (Plaut & Landis, 1992) and as such it remained the focus throughout the programme. This resulted in each community having a unique emphasis, atmosphere, set of dynamics and challenges. For the researcher, this at times proved to be frustratingly time-consuming and disorganising. Even though an ethic of participatory action research had been adopted, the researcher had a pre-determined objective, i.e. to evaluate the effectiveness of two specific aspects of this programme: the SP and the SGTP. Rigid adherence to the ethics of participatory action research (Collins, 1999) and strict application of research ethics (Durrheim & Wassenaar, 2002) are believed to have been the most significant, and the most challenging, aspects that contributed to the success of this programme. Spending time talking, finding out about customs and past experiences, debating the accuracy of translations, chatting about ordinary life events, listening to the life stories of individuals are not only interesting but also of crucial importance (Meintjes, 2004). These activities added a dimension of genuine transparency to the discussion about the ethics of the research. Informed consent can only be obtained once there is a degree of equality and openness within a relationship (Bhana, 2002). Negotiating the aspects of confidentiality in a formal and serious manner added this dimension of credibility that had not altogether been anticipated. SP participants, for example, noticed that the researcher would take the signed 'pledges of confidentiality' home with her each day and they attributed a special significance to this action. In truth, this practice was based on separating out training materials needed for the entire duration of the programme and those parts of the training materials that needed to be safely filed and locked away. However, the communities' attribution of meaning to this practice reinforced the seriousness of the confidentiality and served to counteract a tendency within communities to gossip. There is little doubt that the community participants believed that their views were important to the researcher, and that she welcomed their input and suggestions. This continuous affirmation was experienced as empowering, serious and was considered to a primary contributor to the success of the programme.

Secondly, participants perceived the method of participatory course facilitation as a demonstration of the principles of PSS. Participants expressed that they had felt acknowledged, valued and respected, while being encouraged to think about complex and critical issues. They were proud of their ideas and the recognition that they received for their contributions. This resulted in the participants feeling motivated, being able to see a way forward and develop sufficient confidence to use their own initiative to take action. In a sense, this was a rather surprising finding. The researcher had spent

many days deliberating on exact course content, scheduling when to introduce which topics and how best to make the material relevant for the specific groups. Yet it seemed that the actual course content was secondary to the manner in which it was communicated to the participants. It was also very heartening to have SP participants report that they had begun to appreciate the knowledge that they had prior to participating in the SP. This confirmed that the objective of enabling people to realise their own resources, knowledge and ability to offer PSS in assisting vulnerable children had been achieved.

Thirdly, the involvement of volunteers from the partnering communities to serve as apprentice facilitators when working directly with vulnerable children served multiple beneficial purposes: (i) It created caring, supportive relationships between vulnerable children and caring adults. This was most evident in follow-up sessions when the apprentice-facilitators would largely discuss concerns about children who had been in the groups that they had helped facilitate; (ii) It created the opportunity, over at least thirty hours of hands-on experience, for the apprentice facilitators to establish different forms of relationships with the vulnerable children in their groups - it shifted the focus from the respectful, obedient and authoritarian approach that had dominated adult-child relationships to respectful, caring and supportive relationships – still at times, incorporating the traditional roles of giving advice and guidance; (iii) It provided opportunities for adults and children to see that expressing ones' feelings and pent-up emotions in a contained environment was beneficial (Kazdin, 2000) and left people feeling relieved, understood and supported – this was especially important since many people are advised to 'forget about their feelings, the deceased and get on with life'. As such it created a forum for the cathartic expression of feelings (Yalom, 1985); (iv) it created opportunities for children to laugh, have fun and to play; and (v) since community members were primarily responsible for conducting the alternate programme for Control Group 1, they had the experience of considering ways in which they could organise fun and interesting activities for children with somewhat limited resources (There was a broad-based activity schedule for this group, but frequently the community volunteers would revise, reorganise, or modify the activities to enhance their interests and the enjoyment of the children).

Fourthly, the SGTP was found to reduce symptomatology, especially depression, and to increase perceived access to social support. Although much time and energy had been devoted to gathering the data required for a 4-way multivariate analysis, it was only during the data analysis stage that this result emerged. The experience of the facilitators and the anecdotal feedback from the children,

primary caregivers and educators suggested that the SGTP had been healing and had improved the resilience of the children concerned. Nevertheless, there were many inherent risks associated with using imported psychometric instruments in the study, using unskilled (but trained) research assistants and working in extreme circumstances where deaths, funerals, child rape and other horrendous events were regular occurrences. The experimental design was rather daring under the circumstances. Nevertheless, having been able to empirically and quantitatively establish the effectiveness of the SGTP under such conditions has implications for its use in other circumstances of childhood vulnerability.

12.2. Community demographics

The nine communities were drawn from three different geographic regions on the assumption that the day-to-day life experiences of the residents of these different communities would differ. The profound poverty across all three geographic regions, however, led to there being more similarities across the regions than differences. The 80,2% rate of unemployment among the Community Profile Questionnaire (CPQ) respondents is a direct contributor to the lack of food security and the high prevalence of various social problems (substance abuse, child abuse and neglect, gender violence and criminality) that in turn increases the extreme vulnerability of many children (Brooks-Cole & Duncan, 2000; Garbarino et al., 1992).

HIV/AIDS is a poverty-related social condition (Richter et al., 2001) that gives rise to diverse behavioural, medical, psychological and social consequences. The poor nutritional status of many of the residents is a major concern. Their inability to access health and social services is a fundamental difficulty that contributes to their sense of powerlessness and hopelessness. The risk and resilience research indicates a poor prognosis in situations in which children observe their parents being unable to cope (Brown & Lourie, 2000; Olson & DeFrain, 2000; Rutter, 1987). When families constantly worry about where the next meal will come from, and perceive their access to basic services to be inadequate, their children suffer (Garbarino et al., 1992). Their day-to-day life experiences continually remind them of their inability to exert control over their circumstances, reinforces their victim status and leaves them feeling discriminated against through their being denied access to resources to ensure basic survival (Brown & Lourie, 2000; McLoyd, 1998).

12.3. Implications of poverty indices for intervention and policy makers

Poverty and inequality have a devastating impact on children's lives (Clacherty, 2004), and yet it has

been estimated that 22 million people in South Africa live in dire poverty, i.e. on an income of less than R144:00 per month (Clacherty, 2004, p. 4). These people struggle for survival with basic shortages of food, clothing, shelter and access to social services. The results obtained in this study are consistent with these findings, in which it was found that 52,8% of the CPQ respondents' households lived on less than R500:00 per month, or a *per capita* monthly income of only R 28:86. This situation is indefensible, bringing with it profound levels of misery and threats to the security of the country (Proudlock & Rosa, 2003; Schöönnteich, 2002). The response to poverty requires multi-sectoral, multi-faceted problem solving at the macrosystemic levels of policy development and implementation. Poverty alleviation programmes, integrated development programmes, capacity building of communities, food and social security programmes urgently need to be implemented. There is little doubt that unless poverty is adequately addressed, then all other programmes are doomed to be of limited effect. The South African government is alleged to have spent R90 million rands on its Freedom and Presidential Inauguration Celebration (SABC News, 26th April 2004). If this figure had been reduced to only ten million rand, then 11,695 more children would have been able to receive foster care grants for a year. This would have given 11,695 families substantial reason to celebrate!

An ethical issue that arises from the profound levels of poverty involves the role of volunteers. Much of the battle against HIV/AIDS is being fought at grass roots levels amongst the poorest of the poor. In the main, they are the people who are offering HBC, taking in orphans, arranging the funerals, offering PSS to vulnerable children, working in community vegetable gardens, etc. In this programme it was not unusual for the community volunteers to help distribute food, juice and fruit at a children' group session knowing that they would not have food to feed their own families that night. This is exploitation! The unemployed are being used to service people who are in dire need, in physically and emotionally draining situations and yet they are receiving no financial rewards for their efforts. Many volunteers are motivated by religious commitment (Gothan, 2003). Many believe that God has given them the ability to help others less fortunate than themselves – this is a view that is consistent with African cosmology. However, this does not detract from the basic exploitation of the system. The narratives that encourage volunteerism due to the magnitude of the HIV/AIDS pandemic need to be challenged as they also serve to perpetuate the link between HIV/AIDS and poverty. It is believed that an appropriate form of poverty alleviation would be to pay those people who render services – the current volunteers. They are in effect doing the work that is the primary responsibility of government and of those who are more fortunate members of the global

community. This would not be in the form of payouts but a reasonable wage for a job undertaken, often with great dedication, commitment and care, under extremely emotionally draining circumstances. It has always been, and always will be, difficult to work with the dying and with the children who are witness to the travesties of this life.

It is important that career progression be considered for those people who are currently offering their services on a volunteer basis. Some universities are currently considering offering certificate and degree courses that would foster a career path for those who are dealing with the HIV/AIDS pandemic. Such courses would fit the current South African Qualification Authority (SAQA) structure in which prior learning and experience is acknowledged and volunteers and community workers would be able to progress their knowledge in a focussed, authentic, accredited and dedicated manner. Kluckow (2004) has estimated that there are currently two million people in sub-Saharan Africa who are seeking qualifications that fit their volunteer/job descriptions to the specific social, health, mental health and educational problems that are being brought about by the HIV/AIDS pandemic. Tertiary and secondary educational institutions need to respond to this need as a macrosystemic intervention and contribution to their countries.

12.4: Implications for further research:

In general, this is considered to have been a highly ambitious research programme that successfully evaluated the effectiveness of the two major components of the community-based intervention: the SP and the SGTP. The SP was evaluated using qualitatively methodology in combination with the number and kind of reported PSS activities that were initiated by community volunteers as a result of their participation in the SP. It was not possible to carefully monitor and record the community mobilisation processes and the community-based initiatives, as the researcher needed to rely on the integrity of the community volunteers to obtain these records. The sustainability of these activities is in the researcher's mind, somewhat doubtful. The community-based initiatives require more careful attention and evaluation in order for the sustainability mechanisms to be better understood.

The SGTP was summatively evaluated using quantitative methodology based on translated versions of a number of psychometric instruments. It had been the intention to use a triangulated data gathering process by collecting information on the children from their parents/primary caregivers, educators and the children themselves. The educators proved to be less than reliable and so this data could not be validly (or reliably) maintained within the research design. However, the lack of co-

operation from the educators is regarded as the biggest shortcoming in the current programme. Educators play a pivotal role in children's lives, and their lack of co-operation in the programme is considered to augur poorly for the well-being of their learners. South African educators are under extreme stress at present. Nevertheless the reasons for the failure of the current programme in relation to the educators 'buy-in' and co-operation needs to be investigated more fully. There is an urgent need to get educators on-board if the numbers of children that are being affected by the HIV/AIDS pandemic are to be reached. Life skills, resilience-building, nutritional and agricultural programmes need to be mainstreamed into the educational spheres as a matter of extreme urgency.

There remains a need to develop a short battery of tests that could be used to monitor and evaluate the effectiveness of programmes that offer PSS to children. The battery of tests used in the current research suggest test items that could be useful in this regard, however there is still a need for more theory development and expansion of understanding within the field of resilience and its' measurement. In the face of the HIV/AIDS pandemic, adequate monitoring and evaluation tools for the measurement of psychosocial support are essential to ensure that resources are directed towards implementing effective programmes with measurable and meaningful outcomes. The quality control mechanisms are essential.

Despite the dire need to develop reliable outcome measures for psychosocial support, the focus also needs to include the subtle, more qualitative changes that occur in children when they participate in group therapy and other programmatic interventions. There was a wealth of information collected in the therapy process notes that still need to be analysed. This could yield significant insights into the experiences of vulnerable children. Of particular interest was the way in which children conceptualise and expressed their life stories. Qualitative analysis of these process notes are likely to inform further theory building in terms of the mechanisms through which resilience is built and sustained within an ecological perspective. This will constitute the next research endeavour undertaken by the current researcher.

The role of self-esteem within African and other collectivist cultures needs further clarification, especially in relation to the processes through which self-esteem may function as a protective factor to enhance resilience or how it may be counter-productive in collectivist cultures. It may be that too much focus on an individual, as opposed to the group, would stifle the functioning of the group and thus be detrimental in the long-term.

The current intervention programme was not successful within the informal settlements. It became clear during the community mobilisation processes that children were not a priority in these areas. Despite being told that children would be sent to rural areas, in preference to being raised within the informal settlement, the researcher saw many children resident within these communities. They are at particular risk of being exploited and becoming HIV infected (Shisana & Simbayi, 2002).

12.5: Challenging the dominant social narratives and paradigms:

Whilst conducting this research, it became evident to the researcher that some of the major social narratives need to be challenged as they may be negatively impacting on the implementation of effective programmes. The major challenges will simply be listed in this dissertation, as the debate around each of the issues is extensive and considered to be beyond the scope of this thesis.

- *HIV/AIDS as a medical condition* that needs to be conceptualised within a medical model of disease. The consequence of this social narrative is that resources are directed towards vaccination, treatment and prevention, and the social and psychological consequences are considered to be secondary in terms of budgetary allotments. This point is clearly exemplified when one considers the battles that have developed around the provision of ART's and the rollout of this treatment programme. For example, in the USA Presidential Emergency Relief Fund (2004), there is a congressional ruling that 55% of this fund be used to purchase drugs. Whilst the effectiveness of ART is beyond the knowledge of the researcher, there can be little debate that the ART debacle has diverted energy away from HIV/AIDS being a social problem.
- *The Children's/Human Rights Approaches.* There is something blatantly bizarre about the children's rights approach at a community level of implementation. There is also a simultaneous danger to neglecting this approach. The tension created through this dilemma is difficult to describe. In the face of dire poverty, one cannot be teaching children about their basic rights, thereby instilling a set of false expectations and entitlement to resources that cannot be realistically provided, but children's rights are the most suitable advocacy tool to be used for basic poverty alleviation, accessing resources and for preserving bio-psycho-social integrity and dignity of individuals, families and communities.
- *Community-based interventions are the best practice models:* There is no doubt in the

researcher's mind that community-based models are the best option for childcare. However, the assumptions and the consequences of this position can be dangerous. Community-based interventions need financial and human resources for them to be effective. Capacity-building activities need to be run in conjunction with poverty alleviation programmes. Community-based interventions may be more cost-effective than foster care or the provision of institutional care for destitute children, but there is little understanding of the costs that are still needed to cover the provision of community-based care. The reliance on volunteer to sustain community-based programmes is not sustainable. Therefore, there needs to be planning on how to shift volunteers onto career paths in which there is adequate training, remuneration and quality control mechanisms in order to protect the rights of the children and of the communities. REPSSI is to be commended for its initiatives in this regard.

- *Children as discrete entities needing to be rescued from the devastation brought about the HIV/AIDS pandemic:* Implicit in the narrative around AIDS orphans is the concept that children are victims and that programmes must be directed towards the needs to children. The social ecological models that have been outlined in this dissertation suggest that unless one works at a community or family level in conjunction with the broader social systems, then one is limited in the outcomes that can be achieved. One must also guard against seeing children in the victim position. There is a need to work with children, who are perceived as active social beings, integral to the solution of social problems. The mere existence of child-headed households establishes children as actively coping in the best way possible for them and one needs to recognise and support this coping. Problem solving needs to take place in negotiation with the children and their community stakeholders.
- *Defining concepts:* When developing policies one usually begins by defining the gate-keeping criteria through which subgroups of people are identified as the intended beneficiaries of these policies. For example, the definitions of children as individuals under the age of 15 years, 18 years or school-going is arbitrary, yet when implemented has dire consequences for the way in which individuals are eligible for resources. The international aid organisations have favoured definitions of children as being under the age of 15 years. Most governments regard children as those individuals who are under the age of 18 years. Translated into practice, this means that children who are 18 years and one month old are no longer eligible for grants intended for children. The fact that their education may have been disrupted for various social and economic

reasons is not taken into consideration, and this in turn compounds the difficulties faced by individuals, families and communities, and can have dire long-term consequences for the people thus affected.

The use of these definitions can lead to prolific reliance on reverse and perverse incentives: the child support grant can lead to individuals deciding to have another child in order to access grants; there may be a need to maintain a CD4 count below 400 in order to be eligible for a disability grant; and so forth. This allows little space for innovative and positive forms of social deviance in which an individual, or group of people, may find other methods of meeting their needs, which do not fulfil the socially recognised norms for fulfilling eligibility criteria.

- *The production units within society are usually household units, and within Africa a single household may function within both rural and urban contexts.* This social fact has implications for the way in which the socio-economic functioning of a family needs to be understood. It gives rise to very different understandings of child development and the way in which, for example, attachment relationships and child-care practices function. Many industrial and western concepts are not relevant within this social ecological context.

There are at this stage no solutions to the above-mentioned problems. They simply need to be tabled for debate so that over time solutions can be constructively sought and developed. Campbell (2003) has highlighted slightly different perspectives that she considers critical to the HIV/AIDS pandemic, and these also require special consideration. There is little doubt however that the HIV/AIDS pandemic calls for innovative problem solving with a focus on the psychosocial consequences. This dissertation offers one method of providing psychosocial support to vulnerable children in a way that incorporates a social ecological understanding of risk and resilience.

Chapter 13

Conclusions

In relation to the research question and statement of hypothesis one can draw the following conclusions:

- It was an advantage to utilise the research ethic of participatory action as this was empowering and served to strengthen the communities awareness and willingness of commit to offering PSS to their vulnerable children. It was possible and rewarding for the community members and the researcher to work in a truly collaborative partnership in an ethical, empowering manner in which the purpose of both parties was adequately served. One of the consequences of this approach was the unique aspect of the programme across the various partnering communities.
- The SP was shown to be an effective method of sensitising participants to the psychosocial needs of vulnerable children and left the participants feeling sufficiently empowered to embark on their own community-based initiatives to offer PSS activities.
- While the results were generally more pleasing in the rural areas, the pervasive poverty across the various geographic regions showed that there were more similarities than differences across the three geographic regions. This programme did not work effectively within informal settlements, where it was difficult to prioritise children on their community agendas.
- The SGTP was shown to be an effective method of ameliorating risk, building resilience and enhancing the apprentice-facilitators ability to apply the principles of PSS.
- The SGTP in combination with the SP was the most effective in ameliorating symptoms and enhancing resilience in the form of greater perceived access to social support. The SGTP in combination with the SP worked most effectively with younger children from rural areas. It seemed that the longer children live within high-risk environments in extreme poverty, the more adversely they are affected.
- The psychosocial profile of vulnerable children differed substantially from the psychosocial

profile of non-vulnerable children. However, there were few differences between the vulnerable children who were orphaned and those rendered vulnerable due to other circumstances.

- Ways of improving the SGTP have been identified and are in the process of being implemented and evaluated. The SGTP and the SP both need to be viewed as dynamic programmes that will need continual revision and modification to better meet the needs of vulnerable children and strengthen their community volunteers. It is especially necessary for these programmes to be translated into local languages.
- Although this study seemed to effectively enhance resilience in vulnerable children, much work still needs to be undertaken to understand the mechanisms through which protective processes operate. There is little doubt however that the children who were the subjects of this study had been exposed to high adversity, cumulative risk factors and many had first hand experience of the death of loved ones.

13.1. Findings in relation to the Hypotheses:

- Hypothesis 1 suggested that orphaned and other vulnerable children manifest distress in similar ways. This was largely found to be true, with the exception of school performance, where it was found that orphaned children make slower scholastic progress than other vulnerable children.
- Hypothesis 2 was supported in that non-vulnerable children were found to manifest fewer symptoms of distress than vulnerable children, be they orphaned or not.
- The aspects of Hypothesis 3 pertaining to self-esteem could not be evaluated since the measure of self-esteem (CFSEI) was found to lack reliability across items and time. The SGTP and the SP were found to effectively increase perceived access to social support.
- Hypothesis 4 was not supported as the community-based criteria to measure childhood distress were found to lack reliability.
- The investigation into Hypothesis 5 showed that those children who participated in

Experimental Condition 1, showed a reduction of symptoms on all the dependent variables.

- Vulnerable children felt that they had more access to perceived social support after participation in the SGTP, especially when this was combined with the SP, and especially for the younger children (Hypothesis 7). The effect of the SGTP and SP on self-esteem could not be measured.
- Hypothesis 8 was confirmed: the SGTP paired with the SP was effective in reducing symptomatology in vulnerable children.

Qualitative analysis of the therapy process notes will yield insight into the risk and resilience factors associated with vulnerable children. This however was beyond the scope of the present research programme.

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