

**THE PSYCHOSOCIAL EFFECTS OF CANCER ON
CHILDREN AND THEIR FAMILIES**

by

VINITHA JITHOO

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Nelson R. Mandela School of Medicine

Faculty of Health Sciences

University of Kwa-Zulu Natal

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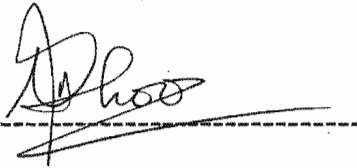
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AUTHOR'S DECLARATION

This study represents original work by the author. It has not been submitted in any other form to the University. Where use was made of the work of others, it has been duly acknowledged in the text.

The research described in this dissertation was carried out in the Department of Behavioural Medicine, Nelson R. Mandela School of Medicine, Faculty of Health Sciences, University of Kwa-Zulu Natal, Durban, South Africa under the supervision of Professor L. Schlebusch.

Signed: _____

A handwritten signature in black ink, appearing to read 'Vinitha Jithoo', written over a dashed line.

VINITHA JITHOO

I certify that the above statement is correct.

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ABSTRACT

Psychosocial oncology is well established in Europe and in America. Similar initiatives are, however, rare in Africa. On the African continent, psychosocial services are scarce and often a luxury although the importance of psychosocial variables as mediators in the paediatric cancer outcomes have been widely recognised. The apartheid system in South Africa was instrumental in causing major disparities in health, education and socioeconomic status. In order to provide a more holistic service it becomes imperative to assess not only the psychosocial needs and resources of both children and parents who endure the disease but also the influence of socio-demographic variables such as race, educational level and socioeconomic status. This research was limited to collecting baseline information on how parents and children communicate about the illness, their emotional responses and the psychological resources that they utilise to deal with the childhood cancer trajectory. The study group consisted of 100 children between the ages of 5 and 16 years who had been diagnosed with cancer and one or both parents of those children. Data was collected through semi-structured interviews and standardised self-report measures. The results of the study indicate that both parents and children did not suffer disabling psychopathology, but certainly evidenced symptoms of depression and anxiety indicative of adjustment difficulties. Communicating about the illness was generally limited to physiological aspects of the disease and medically related matters, while emotional issues were rarely articulated. Children, parents and their siblings relied heavily on medical staff for their information needs. The age of the child was a significant factor with reference to the amount and complexity of information imparted to children: adolescents were given more information about the treatment and prognosis; while younger children were given a limited amount of information. Race, socioeconomic status and educational levels of parents, not only influenced the meanings and beliefs families developed around the cancer experience, but also the manner in which they expressed their emotions and the coping strategies that they employed.

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CHAPTER 1

INTRODUCTION

Children and their families who have to cope with cancer, encounter a long and difficult journey, fraught with exacerbations and remissions, anticipated cures and dreaded recurrences, hospitalisations and discharges, progressive and invasive treatment regimens, and, in general, a physiological and psychological rollercoaster existence (Mc Naull, 1985). From the time they enter the health care system for diagnosis, treatment, rehabilitation and follow up surveillance, individual cancer patients and their families spend an unbelievable amount of time and resources trying to gain control of this physiological disequilibrium. The quality of their existence is not related solely to their physiological condition, but to a complex web of psychological responses to the illness and treatment of a dreaded disease. At a sociological level, the repercussions include: role changes; withdrawal from society; responses from relatives and friends; and cultural factors such as attitudes and beliefs about - *inter alia* "being sick", "unclean" or "helpless".

Childhood cancer once regarded almost without exception as a fatal illness, is now generally regarded as a chronic life threatening disease as a result of: advances in diagnosis; multimodality chemotherapy; ie. a combination of chemotherapy, surgery and radiation therapy; multi-centre national and international trials involving hundreds of children; and, treatment in specialized children's cancer units which are staffed by trained paediatricians. Notably the prognosis has shifted from despairing gloom to guarded hope. In the past, the role of the clinician treating a child with cancer was limited, in the main, to offering support to grieving family members, providing palliative care to the child and helping the family to prepare for death (Koocher, O'Malley, Gogan, & Foster, 1980). However, with increasing numbers of paediatric patients surviving cancer, it is important

to identify factors, which contribute to the long term psychological adjustment of these children.

The person with cancer and the theoretical body describing the illness profile and process is to some extent socio-historically constituted through language and discourse. Thus the psychosocial response to cancer is not necessarily a fixed or stable ('natural') response emanating from individual subjects (determined by personality traits, stimulus-response, learned behaviour, physiological response to stress, etc.) but is a response conducted by and through the various meaning systems contextualising identity and self of the person with cancer, as also the meaning systems which are in turn embedded in the broader social structures of society. Illness is a subjective experience and it is influenced not only by one's biological state but also social and cultural factors and other situational variables. One's perception of cancer will determine when treatment is sought, the type of communication that exists about the illness, whether cultural sources of healing were elicited, the coping skills and the emotional resources of the child and the family. Education about the nature of the disease, its treatment and its consequences, may play a crucial role in changing perceptions and helping people cope with cancer.

The psychological and social factors relating to childhood cancer have been documented in a number of studies (Sawyer, Antoniou, Toogood, & Rice, 1997; Vance & Eiser, 2002; and Woodgate & Degner, 2003), conducted in Europe and America, based predominantly on research on Western cultures. Its relevance to a non-Western context is debatable. A paucity of information exists with regards to developing societies such as those in Africa generally and South Africa in particular. According to Schlebusch (1998), future research priorities identified by CANSA, include research pertaining to children and their families. Accurate statistics on the incidence of childhood cancer in South Africa have not yet been published, but it is hypothesised that the incidence is lower in children than in adults. According to Poole (2003), preliminary data suggested that South Africa has a prevalence rate of 70-80 cases per 1 million children annually. She asserts that there are many reasons for this, those include poor reporting of newly diagnosed cases, failure to diagnose cancer in children at the primary health care level and failure to refer children to

paediatric oncology treatment centres.

Parental reaction to the diagnosis of childhood cancer has been studied (Chesler & Barbarin, 1987; Kazak, 2001; and Van Dolgen-Melman & Sanders-Woudstra, 1986), and three major challenges identified, namely: adjusting to the diagnosis of a life threatening illness; dealing with medical decisions and services; and coping with the disruptions of family life.

In South Africa, we have a unique heterogeneous country comprising of a wide array of income groups, cultures, ethnic origins, languages, traditions and religions. The legacy of apartheid resulted in gross disparities in the provision of health services to this country's populace. According to Poole (2003), only half to two thirds of the malignancies in Black children are diagnosed and 80% of those who are diagnosed present with advanced stage of solid tumours resulting in poorer survival rates. Our knowledge of people's perceptions of the illness, communication patterns, child-rearing practices, psychosocial and educational needs and how they handle grief is inadequate. Additionally, we need to ascertain the psychological implications of the diagnosis of cancer in lower socioeconomic families, especially amongst those from the previously disadvantaged communities of South Africa. Once these issues are clarified, the psycho-social support needs of the population can be identified and provision made to help patients and their families cope better with the disease and treatment.

A child's chronic illness inevitably tests a family's emotional, organisational, financial, and adaptive resources. According to Librow (1989), the damaging effects on individual family members and the family structure include problems such as family isolation, over-involvement of an ill child and a caretaker parent, maternal depression, emotional problems in siblings as well as the chronically ill child. A life threatening disease in a child evokes a wide range of emotions such as fear, grief, despair, helplessness and depression. Parents as well as children suffering from the disease, find themselves in a situation dominated by uncertainty and uncontrollability. Parents fulfil a key role in the acquisition of information about the disease and in communications about the emotional

experience of the disease. In order to avoid being overwhelmed by the negative emotions and to reduce feelings of uncertainty and uncontrollability, the child and his/her parents are forced to appraise the situation in such a way that it will be understandable, acceptable and bearable for them. Hence, communication about the disease also offers the opportunity to express emotions and to find emotional and social support.

The stresses inherent in the cancer experience are different for the child and the family (Chesney & Chesler, 1996). The impact of cancer on healthy siblings has been inadequately studied. The psychological impact on this group of children needs to be assessed. At the time of the diagnosis, parents inevitably focus their energies on the sick child and as a consequence other children in the family have to cope with their parents being less available both emotionally and physically. Identifying and dealing with the emotional needs of healthy siblings would reduce the disruption in interpersonal relationships and foster support and understanding for the sick child as well as parents.

It is important to ascertain not just how South African children conceptualise this life threatening disease, but also what their emotional resources are with regards to coping with pain, discomfort, changes in their bodies, hospitalisation and how this affects their re-integration into the family, school and society. These dimensions are important in helping children deal with the stress of cancer and developing a multidisciplinary collaboration in the treatment of childhood cancer. The aim of this thesis is not to 'disprove' the successes of mainstream psycho-oncology, but to contribute in a profound way to an important body of knowledge, out of a deep personal commitment, in an endeavour, hopefully, to improve the lives of children and their families who have to cope with cancer. In the South African context, the results of this study will be important, primarily, because the prevalence of cancer may be higher than current statistics reveal and proper psychological counselling available to few.

This author, like many others in the field, has been personally captivated by the psychological strength and tenacity exhibited by the children and their families in coping with the onerous burden of the cancer diagnosis. Hence, this research will examine the

following broad dimensions to answer questions pertaining to a range of psychological and social factors which form part of the experience of childhood cancer.

- What are the specific challenges posed by the disease to (a) the child and (b) the family?
- How do parents communicate about the physical and emotional dimensions of childhood cancer with sick children and their siblings?
- How effective is family functioning in those areas most critical to illness management?

Chapter 2 examines childhood cancer with reference to the characteristics of the disease, its incidence in South Africa, as well as the treatment and prognosis. This information helps to trace some of the advances in the medical field which has led to changes in the categorisation of the disease from an acute illness to a chronic illness. The major implications of the re-categorisation, has been the recognition that childhood cancer has long term bio-psychosocial *sequelae*. Thus, the need to anticipate and plan effective health care services which span the entire spectrum of the illness experience.

Chapter 3 examines how the character of children diagnosed with cancer and their immediate support systems that we read about in various sources of literature are conceptually explained and understood by the different theoretical frameworks. It adopts an eco-systemic perspective in exploring the variety of pathways traversed by the cancer trajectory. These theoretical approaches provide a conceptual basis for understanding the factors and mechanisms which mediate the psychosocial responses to illness and thereby aid in predicting successful or unsuccessful outcomes.

In chapter 4 of the thesis a detailed review of the literature on psychosocial oncology is outlined to elucidate the nature of the problem. It explores how the personal experiences of children with cancer are constructed and reconstructed through discourses influenced by knowledge systems as well as cultural influences to reveal the strengths and vulnerabilities of children and their families. It examines how the multiple layers of systems interact to either help or hinder psychological adjustment to illness. A child's

chronic illness has the potential to be one of the most devastating events in the family's life cycle. Its effect is usually determined by a range of factors such as the illness itself, the developmental status of the affected child and family system and the larger context of the community and social supports. It is therefore meaningful to understand how children and their families communicate about illness and develop an understanding of psychosocial oncology.

An empirical study using primary data in the form of a survey is presented in chapter 5 and 6. The study will be enriched by the application of descriptive and inferential statistics used to understand the various parameters under investigation. The thesis will conclude (chapter 7) by examining the following psychosocial variables: communication about the illness; psychosocial adjustment/maladjustment to illness; and, coping strategies used to deal with the illness.

CHAPTER 2

CHILDHOOD CANCER

2.1. CHARACTERISTICS OF THE DISEASE

With the possible exception of AIDS, no disease is more feared than cancer. Part of the reason for this is the common perception that cancer is an insidious degeneration of the body which leads to a slow and painful death (Berman & Wandersman, 1990). Although cancer afflicts all living organisms and has been around since the time of the dinosaurs, a scientific understanding of cancer only developed in the 1970s (Bishop, 1994). Research has led to tremendous strides in understanding the biological mechanisms by which cancer begins and progresses, as well as the ways in which the biology of cancer is intertwined with psychosocial factors. The concepts of 'disease' and 'illness' have been used interchangeably in the literature. For the purpose of this thesis these concepts will be distinguished in accordance with the distinction made by Schlebusch (1990): 'disease' is a physical or organic cause or determinant characterised by structural, functional and biochemical changes and refers to a biological process in which the organs etc. of a patient are affected, whereas 'illness' is the effect of, or response to the disease and as such implies a subjective psychological and social experience open to interpretation by the patient and society.

Cancer is a general term used to describe diseases that involve an uncontrolled growth of cells. Although the single term 'cancer' is used it refers to a variety of different diseases, each, affecting different tissues and organs. These diseases are dangerous because abnormal cells or tumours grow in dangerous sites or near vital organs or because they spread to other parts of the body disrupting normal organ functioning. Cancer cells can break away from the tumour and enter the bloodstream or the lymphatic system,

spreading from the original cancer site to other parts of the body. It may occur as a solid tumour which can spread (metastasize) or as a leukaemia (cancer of the blood).

Typical malignancies occurring in childhood are sarcoma and blastoma. Sarcoma is a malignant growth of connective tissue, for example: osteosarcoma and Ewing's sarcoma (bone tumours), rhabdomyosarcoma (tumour of the muscle tissue) and fibrosarcoma (tumour of the connective tissue). A blastoma develops from embryonic tissue, from blastema which is present in each immature organ, for example nephroblastoma or Wilms' tumour (kidney tumour), hepatoblastoma (liver tumour), medulloblastoma (brain tumour), neuroblastoma (tumour in the sympathetic nervous system) and retinoblastoma (tumour of the eye). Lymphoma is a tumour of the lymph tissue, because lymph tissue is in many parts of the body, lymphomas can start anywhere. Cancers occurring in the lymph tissue are: Hodgkin's disease (affecting lymph nodes close to the body surface, such as the neck, armpit or groin area), Non-Hodgkin's disease (affects lymph nodes that are found deeper in the body, such as the bowel) and Burkitt's lymphoma. Leukaemia is a group of malignant neoplasms in the bone marrow and blood, which if not stopped, displaces healthy tissue and organs and causes loss of function to vital processes and can be terminal. Acute lymphoblastic leukaemia (ALL) is the most common childhood cancer, usually occurring between the ages of 2 and 8 years.

Because the presenting symptomology of cancer may be quite varied and non dramatic (eg. joint pain or swelling, low grade fever of long duration or fatigue and loss of skin tone and pallor) cancer in a child may develop for a long time before a firm diagnosis can be made. A series of procedures/tests (blood tests, bone marrow aspirations, spinal taps, tissue biopsies, x rays, etc.) are used to ascertain the existence of the malignancy and assess its type and extent. Although there are a number of risk factors for the cancers that occur in adults, the aetiology of most cases of childhood cancer is unclear. Van Veldhuizen and Last (1991), suggest that the following etiological factors may play a role: congenital chromosomal defects, ionized radiation, certain chemical substances and possibly even viruses. Amongst the possible factors related to cancer incidence, psychological factors and stress, have been mentioned, however, there is little or no

evidence to suggest that psychosocial factors are associated with the aetiology of childhood cancer.

2.2. INCIDENCE OF CANCER IN CHILDREN

Second to accidents, the most common cause of death among children in the Western world is malignant disease. However, in developing countries, such as South Africa, which is still recovering from the harsh ravages of the apartheid system which left the majority of its population with: high levels of poverty and unemployment; inadequate housing, sanitation and health service provision; and, high levels of illiteracy cancer is superseded by HIV/AIDS and respiratory and nutritional causes as a primary reason for death among children. According to Poole (2003) the relative incidence of various childhood cancers are: leukaemia 34% (acute lymphoblastic 27%, acute myeloid 7%), brain tumours 22%, Embryonal tumours 16% (Wilm's 6%, neuroblastoma 6%, retinoblastoma 3%, hepatoblastoma 1%), lymphomas 11% (Hodgkin's 7%, non-Hodgkin's 4%), sarcomas 11% (soft tissue 6%, bone 5%) and other tumours 6%. The most common childhood cancer both worldwide and in South Africa, is leukaemia, accounting for one third of all cases, followed by lymphomas and tumours in the brain and abdomen (Poole, 2003).

In South Africa at least two thirds of the malignancies remain undiagnosed probably due to a lack of knowledge or resources. In addition, survival rates are reduced or poor among Black children as 80% of them present with advanced stage disease of solid tumours (Poole, 2003). In Western countries, brain tumours account for approximately 20% of childhood cancers. Poole (2003), found that the diagnosis and referral rate of childhood brain tumours in South Africa is much lower. She speculates that the reason for this trend is that many Black children die before being diagnosed. African children appear to have a higher incidence of Wilm's tumour of the kidney and retinoblastoma of the eye.

2.3. TREATMENT AND SIDE-EFFECTS

The precise nature and duration of treatment depends on the type of cancer, its location, the degree of growth and spread of the tumour and other prognostic indicators. The decision to treat at an in- or out-patient level also depends on treatment intensity and the occurrence of complications. The same treatment modalities are applied in the therapy of childhood cancer as in the therapy of cancer of adults, for example; surgery (to remove the cancerous tissue); radiotherapy (to obstruct the division and growth of cancer cells); chemotherapy (to destroy cancer cells or keep them from reproducing); and biologic therapy including bone marrow transplantation. Often, different treatment modalities are combined.

Some side effects are temporary while others represent unavoidable, permanent consequences of aggressive cancer treatment. The medical side effects related to disease and treatment can include: disorders in growth and puberty, obesity, neuropsychological defects, musculoskeletal abnormalities, infertility, learning disabilities, persistent fatigue, and cardiopulmonary problems. Besides organ damage and loss of functions, radiotherapy increases the chance of development of a second tumour or leukaemia. The most prevalent side effects are: nausea, vomiting, loss of appetite, infection of the mucous membranes, hair loss, skin irritations and sensory as well as motor disorders.

2.4. PROGNOSIS

In the absence of effective methods to diagnose and treat children throughout most of the 20th century, many children have died from cancer. Early psychosocial intervention thus focused primarily on preparing children and their families for death. Since the late 1970's, remarkable progress in the medical field has resulted in approximately 70 - 80 % of children surviving, hence childhood cancer changing its categorisation from an acute illness to a recent conceptualisation as a chronic illness. However, Kazak (2001) cautions that despite the increasingly optimistic rates, about a third of all the children with cancer will die from their disease or treatment. In paediatric oncology it is not possible to declare

with an element of certainty that a child is cured because clinical methods are lacking in determining whether cancer cells have been destroyed at the end of therapy. Thus treatment results are usually expressed in terms of survival rates.

Due to high levels of toxicity of treatment long term survivors of paediatric cancer are at risk of developing new cancers, necessitating continuous medical follow up. These follow up appointments usually involve several painful diagnostic procedures (for example, bone marrow aspiration and lumbar puncture) and are approached by children and their families with anxiety and guarded optimism (Rait, Ostroff, Cella, Tan, & Lesko, 1992). Viewed from this perspective, childhood cancer is a chronic medical condition associated with long-term physical, psychological and social consequences.

2.5. CONCLUSION

Major advances in the medical field pertaining to the diagnosis and treatment of childhood cancer have transformed its definition and classification. The disease used to be categorised as an acute disease with a fatal course: remission, relapse and death. Rapidly expanding medical knowledge and technical advances have enabled many children with cancer to live longer and enjoy a better quality of life, thereby transforming the categorisation of cancer to a chronic illness. Despite these advances, there is no certainty about the cure as the term remission can mean both the absence of and latent presence of symptoms. Thus, the life threatening nature of the illness is as ever present as in acute illness. The physical effects of the disease are its most obvious manifestations, whilst the psychosocial aspects are less overt and tend to be more easily ignored or minimised.

CHAPTER 3

PSYCHOSOCIAL THEORIES OF ILLNESS AND ADJUSTMENT

Illness is not simply a personal experience; it is transactional, communicative, profoundly social. The study of illness meanings is not only about one particular individual's experience, it is also very much about social networks, social situations, and different forms of social reality. Illness meanings are shared and negotiated. They are an integral dimension of lives lived together....Illness is deeply embedded in the social world, and consequently it is inseparable from the structures and processes that constitute that world...(A)n enquiry into the meanings of illness is a journey into relationships.

Arthur Kleinman

Heralding as it does a host of changes and challenges, the diagnosis of a chronic illness (like childhood cancer) is a significant source of stress to both children and their families. An immediate response may be one of shock and disbelief. Schlebusch (2000) suggests that many authorities recognise that psychological or behavioural factors may play a potential role in the presentation or treatment of almost every general medical condition and may precipitate or worsen many of their symptoms eliciting stress-related physiological responses. According to Bishop (1994), the stress related to cancer can be understood in terms of a crisis, a situation that is so novel and so major that the person's usual methods of coping are insufficient and in consequence, experiences a state of psychological, social and physical disequilibrium. Whilst in this state, usual responses to situations are disorganised and the person is likely to experience intense emotions, such as fear, guilt and other unpleasant emotions. Throughout this phase patients (and their families) are faced with adaptive tasks such as: dealing with symptoms and coping with

the treatment process; maintaining adequate relations with health care personnel, family and friends; preserving an adequate emotional balance; and, satisfactory self-image as well as preparing for an uncertain future. This phase is usually a transition period, which has implications for later adaptation. Therefore, Schlebusch (2000) suggests that health cannot be viewed from a purely medical, psychological or social point of view, but should be seen as a marriage of the three.

Various models have been proposed for explaining and directing research on the psychosocial impact of illness and adjustment. Most have been constructed around concepts of stress and coping. Many theories have been developed to explain what stress is, how it works and how it relates to health. Rice (1999) contends that theories are the explanatory stories of science, which summarise a body of data and provide an organised, coherent picture of some aspect of human behaviour. There is substantial evidence that stress does impact on health through a variety of pathways and mechanisms. Research conducted by Schlebusch (1997) in suggests that stress response can be conceptualised as following two pathways: (i) a psychological one in which people tend to experience alternating periods of acknowledging the event that caused the stress and blocking it out of conscious awareness; and (ii) a physiological route in which the noradrenergic and endogenous opiate systems as well as the hypothalamic-pituitary-adrenal axis are hyperactive thereby causing psychological or physiological disorders. The following review will examine some of these perspectives (the biopsychosocial model; stress and coping; and, family coping and adjustment) in order to understand the wide variations which characterise the impact of illness and adjustment. These theoretical approaches have implications for understanding the differences between adaptive and maladaptive coping.

3.1. PSYCHOSOCIAL DIMENSIONS OF ILLNESS

What happens, when the initial shock dissipates and the reality of the disease becomes apparent? It is at this point that the struggle begins. Children diagnosed with cancer and those around them, are faced with significant challenges both psychologically and

socially.

Psychological Aspects

Emotional and cognitive dimensions influence adjustment at a psychological level. A major concern in the long-term adjustment to cancer is the range of emotional responses it elicits (Wallace, Blacklay, Eiser, Davies, Hawkins, Levitt, & Jenny, 2001). The diagnosis of cancer is known to produce considerable emotional distress. Initially, the person's response is likely to be one of denial, shock, fear, anxiety, anger, shame and worthlessness. The nature of the illness, its severity and course, and the direct threat to life influences the psychological concerns and outcomes. For the child with cancer, despite a possible 70-90% rate of remission for some forms of cancer, the terror of death at diagnosis is pronounced. While the intensity of emotions may lessen with time, emotional adjustment remains critical.

Closely related to emotional adjustment is cognitive adjustment. Cognitive adjustment is reflected in people's philosophy of life and the meaning they give to events, for example beliefs that people have about their diseases, what caused it, how much control they feel they have, the meanings they can find in events and how they view themselves. Bishop (1994) asserts that although chronic illness and disability are objectively undesirable events, people are quite adept at finding positive meaning in the midst of catastrophe. Although not everyone is able to find a positive meaning, being able to do so, was often associated with better adjustment.

Social Aspects

The challenges associated with childhood cancer can alter interpersonal relationships significantly. External resources and support systems can have a positive effect on the adjustment of the child and family. Interpersonal networks are seen as either protecting individuals from the detrimental effects of stressful life events or enhancing their life regardless of life stress. Both the way the family functions and the effect of the illness on

the family, influence the child. The emotional wellbeing of parents, siblings, grandparents and significant others, and their style of coping directly affect the child, either through the modelling process or through its altered impact on the emotional tone of their environment. The social support network can provide the child with emotional and practical support and often plays a key role in adaptation.

Psychosocial reaction to illness refers to a set of cognitive, emotional and behavioural responses induced in every sick person by all illness related information they receive from: somatic perceptions; the patient's knowledge of and beliefs about the disease; and, messages from the social environment especially the doctor's statements. Not all children with the same condition develop the same psychosocial problems. The coping resources that people mobilise in response to stress plays a key role in determining the nature and extent of the stressor's impact. Thus, in its role as a mediator of the effects of stress, 'coping', is an important component in the mind-body relationship.

3.2. STRESS AND ILLNESS

The term stress conjures up different meanings for different people. Throughout the twentieth century, models of stress have varied in terms of its definition, the differing emphasis on physiological and psychological factors and the description of the relationship between individuals and their environment (Ogden, 1996). Stress has been defined in three basic ways: as a stimulus, a response or a transaction.

One of the earliest models of stress was a physiological model developed by Seyle in 1956, called the General Adaptation Syndrome (GAS). Seyle (in Van Veldhuizen & Last, 1991), defined stress as 'the condition which manifests itself as a specific reaction pattern and consists of all changes created within a biological system by non-specific factors'. The stress response is delineated into three phases: alarm, resistance and exhaustion. This model has been criticised for being too biological and making no attempt to understand the emotional experience of stress and treating good and bad stressors in the same way. Later contentions revealed that different stressors may produce different physiological

responses.

According to the stimulus view, emphasis is placed on the influence of prominent events in one's personal life, one's ability to adapt and on the individual's state of health. This perspective assumes that different people respond similarly to given events and thus the amount of stress that people are experiencing can be determined by assessing the events that have occurred in their lives (Bishop, 1994). The Social Readjustment Rating Scale (Holmes & Rahe, 1967, Rahe & Aurther, 1978) is an example of such a measure.

Bennett (2003) asserts that "in the 1970s, Lazarus and his colleagues began developing one of the most coherent and influential models of stress which took into account the psychological components". According to this view, an event is only stressful based on an individual's cognitive interpretation of it. Hence stress is defined as a transaction between the person and the environment that includes a person's appraisal of the challenges posed by the situation as well as available coping resources, along with psychological and physiological responses to those perceived challenges (Bishop, 1994). The two most important factors according to this perspective are appraisal and coping.

Perception and evaluation of the situation are the cognitive processes of interpretation which precedes the emotion. Lazarus suggested three appraisals that provide meaning and influence the coping process. *Primary appraisal* yields an initial evaluation of the challenge posed by the situation, whilst in *secondary appraisal* an assessment is made of the resources available for dealing with the challenge, and *reappraisal* is based on feedback from transactions which occur after the first two appraisals. It concerns the changes in evaluation as a result of changes in the situation, which could partly be the result of the person's own actions. Lazarus and Folkman (1984), use a transactional model to define stress in order to accentuate the dynamic reciprocal relationship between the individual and the environment. Coping is the second major process involved in the stress experience. Coping depends on appraisal, but conversely the results of coping are likely to alter a person's appraisal. The coping process will be discussed later in this section.

Unlike acute illness, chronic illness does not go away. Wikler (in Figley & McCubbin, 1983) suggests that the child may become better or worse at times but always remains less healthy than the normal child. This situation must produce recurrent stress for families. Figley and McCubbin (1983), allude to the following stressors which will be elaborated upon in the literature review chapter:

1. *Strained family relationships* frequently reflected in (a) over-protectiveness, which interferes with the child's quest for independence; (b) coalitions between the primary caretaker and child, which leave other family members feeling alienated; (c) worry/resentment about additional parental responsibilities; (d) sibling competition and comparisons to the sick child; and, (e) overall increase in family tension and conflict.
2. *Modifications in family activities and goals* such as (a) reduced flexibility in the use of leisure time; (b) reduced career opportunities for the primary caregiver; and (c) uncertainty about whether to have more children.
3. *Burden of increased tasks* such as extra appointments to medical facilities, prolonged separations as a consequence of hospitalisations, etc.
4. *Limitations in social interactions* either from being unavailable to pursue the relationships outside the family due to fear of germs, or lack of time and energy, or being stigmatised.
5. *Medical concerns* related to (a) understanding, clarifying and verifying medical information; (b) the family's ability to follow prescribed treatments at home; and (c) uncertainty regarding prognosis.
6. *Differences in school experiences* such as educational monitoring from the home or hospital contexts.
7. *Grieving* associated with anticipation of death, restricted life opportunities or developmental delays or abnormalities.

3.3. THE SYSTEMS MODEL

The traditional biomedical model assumed that disease could be reduced to biological variables, which were measurable, and thus the task of the health care provider was to merely identify and treat biological factors such as infectious or toxic agents. Thus medical providers were viewed as objective outsiders who assessed, diagnosed and treated their patient's disease. This stance not only failed to acknowledge how physicians may influence and be influenced by their patient's behaviour, but also ignored other relevant dimensions, such as social and psychological factors. Baird and Doherty (in Akamatsu, 1992), state that "focusing only on the biological level represented a cultural bias disguised as scientific theory".

Psychological and physical health and illness are related. Exactly how they are related has been the subject of debate and research for centuries. At one time medical science was dominated by a dichotomy that identified some diseases as "psychosomatic" while others were regarded as "organic" (Wood, 1993). This dichotomy is now invalid, as it subscribed to the mind-body dualistic theory, thereby adopting a reductionistic stance, which ignored the influence of other variables. Ray (2004) empathically asserts that the causes, development and outcomes of an illness are determined by the interaction of psychological, social and cultural factors with biochemistry and physiology. He suggests that the mind - a manifest functioning of the brain, and the other body systems interact in ways critical to health, illness and well-being.

The family systems model grew out of the biopsychosocial model and represents a major departure from the traditional biomedical approach in that it considers all patient problems within the larger social and family context and health care provided by a collaborative team consisting of both medical providers and mental health professionals. The family systems approach emphasises the family level or context as the primary arena in which medical care issues are addressed. According to Campbell, Mc Daniel and Seaburn (1992), four key concepts are core to this family orientation:

- The family is the primary source of many health beliefs and behaviours, hence the

initial appraisal of physical symptoms are made based on these beliefs.

- Stress that a family feels when going through developmental transitions can become manifest in physical symptoms.
- Somatic symptoms can serve adaptive functions within the family and may be maintained by family patterns.
- Families are a valuable resource during illness.

The systems/biopsychosocial approach makes it clear that a person's health status is a product of many different influences ranging from cellular and the biochemical to the social and cultural. Hence changes in a person's health status will have concomitant effects at the psychological, social and cultural levels. General systems approach argues that nature is best understood in terms of a hierarchy of systems in which each system is simultaneously composed of smaller subsystems and is a component of larger more encompassing systems. Each of these system levels are seen as interdependent with events at one level having "ripple effects" on other levels (Bishop, 1994). An important feature of this approach is that change or disturbance at one level affects not only that level, but levels above and below it.

The family meets the basic requirements of a system in that the members are related to one another in a network of interactions. Turk and Kerns (1985), proposed that the four basic characteristics of a family system are (a) it is an open rather than a closed system and has a continuous interchange with the external social and physical environment; (b) it is complex with an intricate organisational structure; (c) it is self-regulating, in the sense of containing homeostatic mechanisms to restore balance; and (d) it is capable of transformation. What is important in this theory is the relationship or interaction between family members rather than the different positions different family members occupy or the content of the communication. Consequently, the family is a powerful determinant of behaviour and can foster adaptive as well maladaptive behaviours. Although there are a number of theories which deal with the adaptation to illness a commonality is the explicit recognition that members of the family are related to one another in a network of interactions. Hence emphasis is placed on the modes of communication and the position

of different family members in the family system rather than the specific content of communication. Linear causation is disregarded in favour of circular causation in which many interacting variables are recognised. An important feature of any system is to strive towards a state of homeostasis, thus, change as a result of illness in any family member would necessitate that other family members adapt.

The cancer related system is formulated in response to the individual, the family and the community joining together to react to the effects of malignant cells in the body of the child diagnosed with cancer. Therefore this system includes: the cancer, the patient's overall health, the person with cancer, the patient's family and the community within a hierarchically arranged continuum. Influences from each level combine to produce the cancer-induced threat.

Threat from the level of *organs, tissues and cells*, determine the biologic realities of the cancer diagnosis and influence the life course of the family. The type and location of the tumour, the stage of cancer spread throughout the body and the availability of treatments for the disease form the basis for therapeutic recommendations, rehabilitation potential and prognosis (Weihs & Reiss, 2000). At this phase the patient and family form a coalition with the medical team to ascertain the nature of the disease and to plan treatment. Cancer treatment is characterised by periods of crises, which require a prompt response from family caregivers and medical personnel separated by quiescent times. Weihs and Reiss (2000), argue that the unpredictability of the illness challenges the ongoing security of the family to defend its vital functions against the cancer intruder.

The *individual* person is confronted with the intrusion of cancer, the side effects of treatment and the person's overall health status. Bahnson (in Weihs & Reiss, 2000) suggests that the uniqueness of the cancer experience leaves most patients feeling as if no other person could understand his/her terror and alienation. The individual's coping; adjustment and experiences of social support shape his/her psychological reaction to the illness.

At the level of the family, the intensity of threat varies according to the phase of cancer treatment: they move between a 'living centred' and 'cancer centred' life course. When the demands of the disease is high, usually during acute phases of illness and treatment, the family functions in a 'cancer centred' modality, devoting personal and financial resources to fighting the cancer while sacrificing other family goals. Once the patient enters the remission phase a 'living centred' life course is resumed, but not to its course prior to diagnosis. Weihs and Reiss (2000), suggest at the societal level, the threat that cancer poses to the family depends on the degree of stratification (by race, ethnicity and geographic location) in society and the degree of its overall resources.

Ostroff, Ross, and Steinglass (2000), encountered four challenges experienced by families entering the survivorship phase of cancer:

- If families persist with being 'cancer centred' during the remission phase, it compromises not only the developmental, practical and emotional needs of the other family members, but that of the patient as well. As a consequence, there is a build up of stress, frustration and poor communication within the family.
- Emotional and behavioural coalitions (often between mother and ill child) that developed during the intensive phase of treatment continue to dominate family relationships during remission. The continued exclusion and isolation of other family members in turn leads to divisive and destructive family interactions.
- These patterns of family response are adhered to rigidly. Illness roles and routine continue to dominate family life; the family has great difficulty switching from a 'day to day' living mode to planning for the future. They hypothesised that the family's ability to change and adjust to the changing demands of cancer may be most predictive of long-term adjustment.
- The rigidity of the family's coping style is sustained partly by the family's relative isolation from friends and extended family. Many 'cancer families' feel that 'normal families' will not understand the practical demands and the shifting emotions that they face daily.

During this phase the family tends to remain in a holding pattern characterised by deferring and delaying major decisions while coping on a day-to-day basis and sacrificing long term developmental tasks. Sometimes this is a direct reaction to ongoing stress, but sometimes it is a 'habit', a resetting of family homeostasis that was changed during a dramatic period and now remains at a new setting (Rait & Lederberg, 1989). An essential feature of the biopsychosocial approach is the concept of self-regulation. Leventhal and his colleagues proposed that systems are goal orientated and use feedback loops to direct their behaviour in order to achieve a balance in their functioning (Bennet, 2003).

3.3.1 SELF-REGULATION MODEL

The concept of self-regulation plays an important part in understanding health and illness because feedback loops are present at every level of the hierarchy. Leventhal (1984) and his colleagues used the self-regulation model, to explain how people represent and cope with the threat of illness. According to this model, the individual faced with a health problem will be motivated to reduce any consequent emotional distress and return to a state of equilibrium by engaging in a variety of coping strategies (Bennet, 2003). The self-regulatory model comprises of three stages, namely: interpretation, coping, and appraisal. These stages continuously interrelate in a dynamic manner to maintain a status quo (i.e. they regulate the self). Therefore, if the individual's normal state (health) is disrupted (by illness) the model proposes that they are motivated to return to a previous state of normality.

Interpretation

The first stage concerns the representation and interpretation of information in order to develop an understanding of the health threat. It is based on information obtained from three main sources namely: somatic perceptions (signs and symptoms of the illness), illness representations (the patient's own knowledge of and beliefs about the disease), and social messages (messages from the individual's social sphere including doctor's statements about the diagnosis and nature of the illness. According to this theory, once an

individual has received this information they are then motivated to return to a state of 'problem-free' normality (Ogden, 1996).

Illness cognitions are constructed along the following dimensions: identity, cause, consequences; time line; and, cure/control. Leventhal, Meyer, and Nerenz, (1980) describes these five cognitive dimensions as follows:

- *Identity*: this involves the label of the illness and the symptoms experienced.
- *The perceived cause of illness*: these causes may be biological or psychosocial.
- *Time line*: this refers to a patient's beliefs about how long the illness will last whether it is acute (short term) or chronic (long term).
- *Consequences*: this refers to the patient's perceptions about the possible effect of the illness on their life. Those consequences may be physical (eg. pain, lack of mobility), emotional (eg. loss of social contact, loneliness) and economic.
- *Curability and controllability*: patient's also represent illness in terms of whether they believe that the illness can be treated and cured and the extent to which the outcome of their illness is controllable either by themselves or by powerful others.

The identification of the problem along these dimensions results in changes at an emotional level. These cognitive representations enable the development of meaning to the problem that further enables an individual to consider, develop and implement suitable coping strategies. Hence, coping strategies have to relate to both the illness cognitions and the emotional state of the individual. Nerenz and Leventhal (in Bennett, 2003), warned that despite a generic underlying structure, illness representations are not always necessarily well integrated or complete.

Social messages will influence how the individual interprets the 'problem' of illness. The experience of illness and the person's response to it are a function of many influences. Culture provides a person with a set of basic illness orientations and conceptual categories of understanding suffering and discomfort. Information may also come from

lay individuals such as friends, family, priests, alternative health practitioners and traditional healers all of whom are not health professionals. Those social messages may result in a lay diagnosis or a suggestion to seek medical help.

Coping and appraisal

The next stage of the self-regulatory model is the identification and development of coping strategies. Ogden (1996) asserted that coping is increasingly implicated as an important factor influencing recovery from illness or surgery and mediating the relationship between stress and illness outcomes. According to the literature base, the coping process includes all aspects of a person's effort to deal with the perceived threat of illness, whether: overt or covert; positive or negative; adaptive or maladaptive. How a patient copes with illness reflects his/her habitual tendencies to deal with stressful life events in individually characteristic ways. White (in Van Veldhuizen & Last, 1991), suggests that coping is related to psychological concepts such as adaptation, mastery and defence mechanisms. The self-regulatory model conceptualises coping behaviour as a stable personality trait developed on the basis of previous learning experiences associated with existing dispositions. Two broad categories of coping have been defined that incorporate a multitude of coping strategies, namely, approach coping (eg. seeking a diagnosis and treatment, talking about emotions) and avoidance coping (eg. denial, wishful thinking). This stance has been criticised as it implies a stable reaction pattern, which cannot be easily adjusted, as the situation requires.

As a response to that criticism other researchers prefer to describe coping behaviour as a style, thereby incorporating a measure of flexibility depending on situational variables. Lazarus and Folkman (1984) consider coping style to be a transactional process between the person and the environment and as such define it as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. On the basis of the individual's reaction to the situation, new evaluations (reappraisals) are made which lead to new reactions. Ogden (1996) endorses three approaches to theories of coping, namely,

coping with a diagnosis, coping with the crisis of illness, and adjustment to physical illness.

Coping with a diagnosis

Shontz (in Ogden, 1996) describes the following stages that the individual goes through after a diagnosis of chronic illness. Most people go through a state of shock which is characterised by being stunned and bewildered; hence they behave in an automatic fashion. That is followed by an encounter reaction, characterised by disorganised thinking and feelings of loss, grief, helplessness and despair. The third stage, a temporary phase, is characterised by denial and a retreat into the self.

Coping with the crisis of illness

Once confronted with the disequilibrium triggered by physical illness, individuals evaluate its seriousness and significance (eg. my cancer is serious, how will my cancer influence my life in the long term). Factors such as knowledge, previous experience and social support may influence the appraisal process. Generally, illness beliefs are related to illness appraisal. Coping is a goal directed activity that people manage in different ways. According to Lazarus and Folkman (1984), the individual may engage in a number of coping strategies to reduce the adverse emotional state associated with appraisals of the threat. Those coping strategies fall into two broad categories: problem-focused and emotion-focused. With problem-focused coping the individual attempts to change the situation thereby reducing its threat. Emotion-focused coping involves strategies aimed at reducing levels of distress whilst leaving the situation unaltered.

Problem-focused coping involves confronting the problem and reconstructing it as manageable and then generating alternative solutions, weighing alternatives in terms of their costs and benefits, choosing among them and acting. These actions are attempts at primary control of the situation. For cancer patients, attempts at controlling the course of the illness, consists of persistence in seeking medical assistance, undergoing and

accepting the aversive consequences of therapy and persistence in attempting to change the situation, even in the face of poor prognosis. Van Veldhuizen and Last (1991), suggest that children with cancer and their parents utilise Rothbaum's primary control strategies, namely; predictive, illusory, vicarious and interpretive control. Interpretive control is gained by seeking information about the illness and treatment programmes in an attempt to understand the situation and to promote possible solutions. The improved knowledge base helps them to develop cognitions about the expected course of the illness, treatment schedule and side effects of therapy. This, results in them achieving predictive control. Illusory control is accomplished by attempts to control the chance occurrences by a change of eating habits and life-style, following the prescripts of religion and rituals etc. After the initial phase of the illness, the patient and their families become more active in the medical decision making process, thereby achieving vicarious control.

Emotion-focused coping strategies involve changing the way one thinks about the situation (for example; denial, avoidance, distancing, minimisation and positive comparison). When primary control is unsuccessful, individuals concentrate on learning to adapt to negative events. Emotion-focused coping is related to Rothbaum's concept of secondary control (Van Veldhuizen & Last, 1991). The predictive, illusory, vicarious and interpretive control strategies also apply at the secondary level. One way in which children diagnosed with cancer and their parents can protect themselves against disappointment is to have predictive control over the condition. That is accomplished by accepting that the disease is fatal and the possibility of death occurring is realistic. Attaining interpretive control is less taxing emotionally as it entails searching for the meaning in the illness and accepting the situation. Those affected often go through a process of intense questioning but hold on to the belief that fate will be kind to them (illusory control). Additionally, children and their parents attribute special power to the doctor, through whom they gain control of the situation (vicarious control).

Coping also follows a developmental sequence which correlates with cognitive development and maturity. Younger children use problem-focused strategies, whilst older

children use emotion-focused strategies. Damon and Hart (1982) state that the ability to reflect on the self; is a developmental process. It is only in late adolescence that relationships amongst one's past, present and future selves incorporated into a fuller definition of self. Both problem-focused and emotion-focused coping are ways of exerting control. As strategies they can be beneficial or detrimental depending on the particular situation.

Individuals appraise the illness and then use a variety of adaptive and coping skills in pursuit of a reality orientation. The mechanisms employed determine the outcome. It is thus not a straightforward process whereby healthy adaptation leads to maturation and a maladaptive response lead to deterioration, as not all individuals respond to illness in the same way. According to Moos and Schaefer (1984), the following factors influence the coping process:

- Demographic and personal factors such as age, sex, class, religion.
- Physical and social factors such as the accessibility of social support networks and the accessibility of the physical environment.
- Illness related factors such as, any resulting pain, disfigurement or stigma.

Adjustment to physical illness and the theory of cognitive adaptation

The process of adjustment is not only an emotional process but also cognitive one. Taylor (in Bishop, 1994), suggests that adaptation consists of three processes:

- The search for meaning: attributions about illness in search of causality, which may not always correspond to a medical understanding.
- A search for mastery: believing that the illness is controllable, efforts include psychological techniques such as developing a positive attitude, meditation, self-hypnosis or a type of causal attribution; or behavioural techniques such as changing diet, changing medications, accessing information or controlling side-effects.
- The process of self-enhancement: finding ways of feeling good about one's self and rebuilding one's self-esteem.

According to this model, these beliefs may not be logical or accurate, but are essential to maintaining illusions that promote adjustment to illness. Therefore, the desired outcome of the coping process is the development of illusions not reality orientation. While the individual perspectives on stress and coping provides useful information about how an individual deals with chronic illness, family perspectives contend that coping with chronic illness is not simply a matter of individual appraisal and response but of the organisation of relationships.

3.4 FAMILY STRESS THEORY

Cancer brings some families together whilst others are torn apart. Either way no one escapes the changes resulting from the invasion of this life-threatening illness. Psychological adjustment depends on the adaptation of family relational processes, which sets in motion either constructive or destructive transformations of family relationships. The family stress theory was originally conceptualised by Hill in 1949. In this theory it is the interaction between the family's resources and the objective event that determines the degree of stress (Turk & Kerns, 1985). According to this model, family resources are seen as important factors facilitating adaptation to crisis situations. Resources include: (a) financial resources, which contribute to economic well being; (b) educational resources contributing to cognitive ability that facilitates realistic stress perception and problem solving; (c) health resources which enhance physical well-being; and (d) psychological resources such as personality characteristics. A number of theoretical models of family adaptation to the crisis of childhood cancer have been proposed and studied. An extended discussion of each of these models is beyond the scope of this discussion. Only two of these frameworks, namely: the *Family Adjustment and Adaptation Response model* and the *Family Resource and Resistance Factor model* will be briefly discussed.

Family Adjustment and Adaptation Response model (FAAR)

Hill in 1966 (in Dolgin & Phipps, 1996), developed the ABCX model to explain family adaptation to stressful events. He presented a framework for family stress theory that

focused on three variables: 'A' the provoking event or stressor; 'B' the resources or strengths of the family at the time of the event; and 'C' the meaning that the family either individually or collectively attaches to the event. He theorised that a stressor event (A) interacts with family resources (B), followed by a family's appraisal (C) of an event, resulting in an outcome (X). This model has been expanded on and adapted by McCubbin and Patterson in 1982 (in Drotar, 1992), into the T-Double ABCX model in order to appreciate the dynamic aspects of adjustment to an ongoing stressor over time. A central concept of this revision is that of 'pile up' of demands on family resources and the identification of coping strategies used by the family. The Double ABCX model suggests that coping is a central tenet of adaptation and the restoration of a homeostatic balance. Coping emerges out of the pile up of demands and involves the interaction of resources, perception and behavioural responses.

McCubbin and his colleagues (in Rice, 1999), specified four general hypotheses of how family coping actions work to ward off stress:

- The first is the notion that coping behaviours reduce family vulnerability. Dealing with the issue satisfactorily may remove the threat thus restoring balance to the family and reducing vulnerability.
- The second hypothesis is that coping actions may strengthen or maintain family cohesiveness and organisation.
- Third, is that coping may reduce or eliminate stressor events.
- Fourth, coping may actively operate on the environment to change it.

In McCubbin's analysis, faulty coping can produce stress as some coping strategies can be misguided, inferior or out of touch with reality. This becomes pronounced when the family engages in denial or refuses to accept reality.

According to the FAAR model family coping is a major resource and is defined as action to either reduce the demands or acquire resources or changing the meaning of the situation to make it more manageable. Drotar (1992) suggests that these meanings may be situational (eg. the family's subjective definition of demands and capabilities) or global (ie. how the family views the relationship of family members to one another, the

community, etc.). Families generally use many resources and capabilities at their disposal in order to meet the demands of the situation. Those include: financial, personal (self-esteem, knowledge, skills) systems resources (cohesion, organisation, communication skills), and community resources (schools, churches, medical care, social support). The meaning that the family ascribes to these demands and their capabilities are critical factors in achieving a balanced functioning. According to Roberts and Wallander (1992), the outcome is conceptualised in terms of adjustment and family adaptation, which represents two phases: (1) an adjustment phase, which is relatively stable and patterns of family interaction are predictable and stable; and, (2) a crisis state of disequilibrium, which emerges when the demands exceed the capabilities of the family.

In crisis situations such as the diagnosis of childhood cancer, stressors or demands on family members may exceed their capabilities. As a response family members may attempt to restore equilibrium by:

- acquiring new adaptive resources and/or coping behaviours;
- reducing the pile up demands; or
- changing the way they perceive the situation.

Family Resource and Resistance Factor model

Varni and Wallander in 1988 (in Drotar, 1992), proposed an alternative framework which accounts for individual variation in psychological adaptation among children with chronic illness. Central to this framework is the distinction between risk factors that are hypothesised to increase the probability of adjustment problems versus resistance factors that are expected to decrease the likelihood of psychological disturbance. Risk factors are described as disease or disability parameters, the child's functional independence and psychosocial stressors. They worked from the premise that the impact of risk factors is moderated by three broad types of resistance or coping resource factors:

- stable interpersonal factors (temperament and perceived competence);
- stress producing or coping ability factors (cognitive appraisal and coping behaviours); and

- socio-ecological influences such as the quality of family relationships, utilitarian resources such as money, etc.

3.5. FAMILY ROLE THEORIES

Role theories analyse the contributions that individual family members make within the family context. According to Hill, the impact of a family member's illness on the health and functioning of the family appears to be related to the roles that members play in that family and the previous global level of health (Turk & Kerns, 1985). Families organised around a particular role structure, for example, a traditional gender divide may experience some difficulty in adjusting their pre-existing values to the requirements of the illness. Pratt (in Turk & Kerns, 1985), suggests that one factor that distinguishes those families who adjust from those who have difficulty, is the ability to be flexible about the roles that they adopt. A second perspective revolves around the role the family plays in contributing to and maintaining 'sick-role' behaviours. Minuchin (in Fiese & Sameroff, 1992), suggests that a child's physical symptoms are a response to conflict in families that can be described as enmeshed, overprotective and rigid.

3.6. TRANSACTIONAL MODEL

Other models presented focused on the family as passive and reactive in response to information concerning health and illness. In contrast, a transactional perspective places an emphasis on the ways in which a family and child mutually create a context for disease expression. According to Turk and Kerns (1985), an alternative way to conceptualise the relationship between health, illness, the family and individual family members is to view both the family and individual members as active information processors who: (a) seek out information and evaluate the features and characteristics of the information or of specific sources of stress and disruption; (b) evaluate resources for responding to the threat; (c) act on the environment and after responding; (d) evaluate the adequacy of the response. In summary, this model emphasises the active interaction amongst family members and their environment.

Society regulates the behaviour of families and children through statutes and normative rules which are culturally based. In turn the family regulates the child's development through its own interpretation of these norms, which may be termed the family code. The family code reflects the family's belief system, the family's definition of itself as different from other families and the structure and organisation of the family's daily routines (Fiese & Sameroff, 1992). Hence the family code is a system of family definitions that are used as guidelines for family behaviour. Fiese and Sameroff (1992), found three areas to be useful in constructing the family code:

1. *Family paradigms* are global belief systems that define the social world of the family. In paediatric psycho-oncology family paradigms provide valuable insights into two areas, namely; (a) how families understand their relationship to health professionals in general, and (b) how families understand their child's medical condition.
2. *Family stories* are based on the recounting of actual events as a means of transmitting values, assigning roles, and preserving customs.
3. *Family rituals* regulate role definition in the context of family routines and activities. Rituals may also provide a buffer against stressful situations in the family and protect family members from disruptive influences of other family members.

3.7 FAMILY PROCESSES THAT SHAPE THE IMPACT OF ILLNESS

In a study on the motivation to become a parent, Out and Zegveld (1977), identified the following clusters: a child is seen as an important object of care and love; a child gives meaning to life and thus contributes to the parent's identity; a child represents vitality; confirms the relationship between partners; is the object of personal goals (through the child parents achieve goals which they never attained themselves); a child is the focus for identification with the larger world of nature or creation and contributes to the link with society (Van Veldhuisen & Last, 1991).

Just as individuals pass through stages of development so does the family. Solomon (in

Koocher & MacDonald, 1992), suggests that the family life cycle comprises of five stages, based on critical tasks to be completed:

- A family begins with a *marriage*, which includes separation from families of origin and investment of primary commitments of marriage.
- The second stage centres on the *birth of the first child* and involves development of new roles as parents without neglecting the marital relationship.
- The third stage, *individuation*, begins when the first child enters school and requires accepting the child's growing independence and also encouraging socialisation.
- In the fourth stage, *departure of children*, parents must learn to let go, while the adult children separate and develop other primary relationships.
- In the fifth stage, *integration of loss*, aging parents must typically deal with losses in economic, social and physical functioning.

Families generally operate on a predictable normative cycle, anticipating and accepting a sequence of events that occur throughout the life course. Seen from this perspective, the diagnosis of childhood cancer falls outside the usual developmental cycle and becomes disruptive and difficult to accept. Koocher and MacDonald (1992), argue that often predictable transitions may cause significant stress the occurrence of non-normative events or normative events such as illness and death at unanticipated times may drain the family's economic and emotional resources and detract attention from ongoing developmental demands.

The relationships between individual family members change constantly in response to life events and interactions which characterise the family life cycle. Langton (2000) suggests that the occurrence of childhood cancer is a major and highly stressful event, which changes the status of the affected member and alters the equilibrium of the family unit thereby creating insecurity and worry.

Cancer poses a threat of separating the child from the family both at a physical and an

emotional level. The manner in which family relationships unfold is believed to modulate the impact of the cancer related threat. Wynne (1988) expanded on Bowlby's theory and applied the findings of other attachment researchers to his epigenetic model of enduring family relational systems to explain the dynamic unfolding of family relationships during the cancer experience. He contends that attachment relational processes become activated by the cancer threat and thus set in motion an epigenetic sequence of development of relational capacities within the family. This model is proposed as a template for distinguishing the stage of development and the type of distortions that might be found among cancer patients. According to this theory if: (a) secure attachments are activated and reinforced through the sensitive responsiveness of family members to the distress of cancer then revisions of other relational capacities are likely to occur without distortion or impasse; (b) insecure attachments are activated they will be expressed as one of three responses: viz. (i) ambivalent-emotionally over-involved; (ii) avoidant-'flat' detached; or, (iii) disorganised-critical and hostile.

Four capacities for relating arise in the epigenesis of enduring relational systems, namely, attachment/care-giving, communication, joint problem solving, and mutuality (Wynne, 1988). Each *attachment* relationship is characterised by a range of closeness and separation which is altered over time and changes in social circumstances. Weihs and Reiss (2000), assert when insecure attachments predominate it may be expressed as over-involvement, avoidance or criticism. This would result in subsequent dysfunctions of communication, problem solving and mutuality. The problem with insecure attachments is that it fails to provide a 'holding environment' in which the distress associated with cancer can be relieved: (1) the patient may not receive a comforting and accepting response, (2) others may become distressed and focused on their own strong feelings (emotional over-involvement), (3) they might become withdrawn from the distressed person ('flat' detachment), or (4) they may become controlling and hostile (Weihs & Reiss, 2000). The cancer diagnosis may alter the life course of some families with insecure attachment styles. In response to the stressor (cancer) they may elicit new and more productive care-giving responses resulting in an improved and fruitful pattern of communicating with shared attention which feeds back to reinforce a more secure

attachment.

Historically, the relationship between families and medical illness has been conceptualised from two broad perspectives, namely, the impact of childhood illness on the family and the impact of the family on illness and disease symptoms. Over the last forty years this field has grown and a series of transformations have taken place. According to Steinglass (2000), the literature has pointed to four ways in which family factors affect the onset and course of chronic illnesses:

- Family pathology/dysfunction as a contributing factor in the development of chronic illness (deficit perspective).
- The family as a resource for the individual coping with medical illness (resource perspective).
- Family factors as determinants of differential clinical course (clinical course perspective).
- Family factors as they influence relationships with health care delivery systems (impact perspective).

Deficit perspective

The most prominent of these deficit models is the 'psychosomatic family' model of Munuchin. According to this perspective the family played a major role in the aetiology of chronic illness. Poor conflict resolution, weak interpersonal boundaries, overprotection of family members and rigid transactional patterns contributed greatly to the development of chronic medical disorders. As a reaction to this body of knowledge, a common response at that time (1960s and 1970s) by health care providers was to remove the child from the family in order to provide a healthier environment for the child's recovery.

This model came under considerable criticism for its poor definitions of its core dimensions (eg. enmeshment); its tendency to pathologise families and its failure to appreciate how stressful chronic illness can be for families. A large portion of the literature prior to 1980 was directed at identifying psychopathology and addressed areas

of weakness and deficit in families. The position taken under this model was that a diagnosis of chronic illness in a child would result in family disorganisation and divorce, with concomitant negative outcomes for siblings.

Resource perspective

Illness is seen as an independent biological entity that afflicts a family. However, the family can alter the course of the illness through its efficacy in dealing with the disease. This perspective is the opposite of the deficit perspective in its contention that the family serves either a protective or preventative role in strengthening resistance to illness and plays a determinant role in successful adherence to treatment regimens once illness is present (Steinglass, 2000). This model is organised around the identification of coping strategies aimed at managing the illness response.

Clinical course perspective

This perspective, similar to the resource view, examines how the family influences the course of illness. However, it works from the assumption that different illness characteristics and phases in the illness process place different demands on the family. Hence, the manner in which the family responds to these challenges is directly related to the individual's adjustment to the illness. Reiss (in Steinglass, 2000), suggests that as the illness moves into the chronic phase families gradually reorganise their daily lives around illness demands eg. daily routines are reorganised to accommodate sleep-wake cycles, mealtime schedules etc. and socialising is based on the energy levels of the patient. Once this process is instituted families sometimes struggle to find the correct balance between illness and non-illness issues in their lives thereby failing to reappraise the changed circumstances, thus maintaining the chronic course of the illness.

Impact perspective

The resource perspective focused primarily on strategies the family could use to improve

the patient's condition to minimise the illness impact on the patient thereby failing to acknowledge the impact of the illness on the family. A substantial literature base exists that suggests that the impact of medical illness on the family as a group is equal to or even more devastating than for the patient alone. This is definitely the case in paediatric cancer where psychological distress levels amongst caregivers were found to be high with many showing signs of clinical depression. Jacobs (1992), suggests that chronic illness has a reorganising effect on family life as it results in emotional distress and the reallocation of roles, hence families must work to protect valued family practices. Steinglass (2000) criticises this approach for being disease-specific and ignoring the different types of psychosocial challenges posed by chronic illness as a whole as well as reinforcing the focus on the index patient with the rest of the family being treated as adjunctive paraprofessionals.

3.8 CONCLUSION

Individuals with chronic and life threatening illnesses face an uncertain future, characterised by cycles of disease activity followed by remission. Dealing effectively therewith requires of patients and their families that they develop various coping skills that may focus on emotions stirred by the illness itself or the practical aspects of the illness. The process of unravelling the factors which influence the patients and their families, at different points in time, is a highly complex task. Theories (such as the attribution theory, attachment theory, stress and coping models, systems theory, family life cycle model, FAAR and family resource and resistance factor model) have been adopted to integrate different beliefs and models in an attempt to predict successful or unsuccessful outcomes.

Health psychology is recognised for its contributions (theory and research) to understanding the interaction between medical illness and psychological factors, thereby forming the basis for an intervention plan that can influence the course and outcome of the illness. Wide arrays of disease and individual and family variables have been included in this theoretical outline as an aid to the conceptualisation and understanding of children

diagnosed with cancer and their families. These theories of circular causality also explain how the multiple layers of systems interact with each other to either help or hinder adjustment.

CHAPTER 4

LITERATURE REVIEW

"From the moment of diagnosis, the illness wends a perilous course, the unknown lies ahead like an uncharted chasm, without boundaries or guides. Cancer is filled with hardship and terror for the child on both a physical and an emotional level, its ravages are an entity to be reckoned with on an ongoing basis, not a psychic abstraction"

(Sourkes & Proulx, 2000:277)

4.1 INTRODUCTION

According to Mattson (1972) chronic illness has been defined as "a disorder with a protracted course that can be fatal or associated with a relatively normal lifespan despite impaired physical or mental functioning. Such an illness frequently shows a period of acute exacerbations requiring intensive medical attention". Cancer a chronic illness differs from acute illness in that: (i) it is treatable yet not curable and thus needs management for long periods of time; and therefore, (ii) the responsibility for the management is shared with and/or transferred to the child and family (Wallander & Thomson, 1995).

The physical characteristics of cancer generally define the objective situation facing the patient. But cancer has far reaching effects on the psychological and social functioning. Hammond (in Rait, Ostroff, Smith, Cella, Tan, & Lesko, 1992), has noted that despite the spectacular successes in developing treatments capable of enabling complete recovery from illness as well as long term survival achieving the "restoration of health, including physical, developmental, functional, and psychological" often fails. The survival rates recorded often do not reflect the challenges faced by children and their families after treatment is completed. There has been much debate in the literature about the severity of

the psychosocial consequences for both parents and children surviving cancer. While some studies claim the effects are minimal, others point to a range of adjustments and psychopathological features. The potential disruption of developmental stages during childhood makes the evaluation of the psychosocial *sequelae* important in developing an understanding of how children and their families adapt to the disease and its treatment.

The coping ability and adjustment of children depends on multiple factors such as risk factors due to the illness itself as well as resistance factors related to the individual. Recent research has focused on trying to identify these risk and protective factors with the hope that a better understanding would help us predict and/or prevent these problems. Broad groupings identified so far include the characteristics of the condition, the personality of the child, the family structure and the community.

Progress in the field of paediatric oncology resulted in the evolution of treatment and prognosis, hence, the psychological, emotional and social issues confronting patients and their families have changed as well. Issues that concerned researchers and clinicians in the past, when childhood cancer was fatal, focused primarily on death. Hence, psychosocial efforts centred on the child and family in preparation for the untimely demise of the child. This has changed with recent successes in diagnosis and treatment. The family now has to deal with uncertainty as a coping task and focus their psychosocial energies on quality of life issues. The field has also expanded to include the experiences of children. This chapter will outline these changes and will summarise the major themes pertinent to the focus of this study. The aim of this section is to review the literature on the psychosocial aspects of childhood cancer with specific emphasis on the impact cancer has on children and their families and the psychological and social resources they use to adjust to and cope with the illness.

4.2 PSYCHOSOCIAL IMPACT OF CANCER ON CHILDREN

Depending on the diagnosis, treatment may comprise of chemotherapy, radiotherapy, surgery, stem cell transplants and bone marrow transplants. In most instances, a

combination of treatment modalities is required. All treatment modalities will have some side effects that may range from short term and transitory in nature, to long term and permanent. Katz (in Van Dolgen-Melman & Saunders-Woudstra, 1986), suggests that the more complex the therapeutic regimen the more this may interfere with the child's rehabilitation. During the course of treatment the child is confronted with threats to physical integrity, safety and security, the loss of life, pain, non participation in sport, games and other fun activities, and intense physical illness. Relapses may also occur either whilst treatment is in progress or after completion. When that occurs treatment may have to be re-initiated, often more aggressively. The emotional impact of a relapse is often worse than the diagnosis. The life threatening nature of the illness is apparent and becomes intensified during times of severe pain, discomfort and illness. Spinetta and Maloney (in Spinetta & Deasy-Spinetta, 1981), noted that the child with cancer experiences more anxiety with the progression of the disease and with each clinic visit. This makes the child more susceptible to psychosocial problems.

The medical treatment and procedures including bone marrow aspirations, lumbar punctures and intravenously administered cytostatics besides causing acute pain, nausea vomiting and severe physical discomfort, also cause acute anxiety (Van Veldhuisen & Last, 1991). The child's vulnerability to feelings of depression, anxiety and helplessness is increased during periods of hospitalisation. In-patient treatment poses several problems as it severely curtails and restricts their freedom of movement, threatens their attachment, familial and peer relationships thereby resulting in social isolation, insecurity and reduced control over their lives. According to Bowlby's theory, hospitalisation results in strong separation anxiety in the young child, who, after a stage of violent protest, reverts to apathy, depression and regressive behaviour if separation from parents is complete and long lasting (Van Veldhuisen & Last, 1991). Thus the child becomes highly dependent on parents to create a buffer between the child and those stressful situations.

Mixed findings characterise investigations of the psychosocial consequences of childhood cancer. Several studies have found a high frequency of emotional and social problems including poor self esteem, poor self-satisfaction, less ambitious ideals, death

anxiety, depression, poor social skills, school re-integration problems and school phobia. Other studies have found normal levels of adjustment. It has been suggested that the contradictory findings could be attributed to factors such as: differences in methodology, and the extreme heterogeneity of participants in terms of diagnosis, age at diagnosis, intensity of treatment and time since diagnosis. These differences were evident in two recent studies. Negative results were attained in the study conducted by Bessel (2001), which examined the psychosocial adjustment, quality of life and school experiences of post-treatment survivors (8 to 17 years) of paediatric cancer using a multi-method, multi-source approach. Children and adolescents in this study exhibited resiliency in the face of adversity, however, 42% of this sample reported social anxiety, poor peer acceptance, self concept issues, feelings of isolation and poor academic performance. However, research conducted by Noll, Garstein, Vannatta, Correll, Bukowski and Davies (1999), used various methods to measure the social, emotional and behavioural quality of life of children receiving chemotherapy from the perspective of peers, teachers and parents, revealed more positive results. Their data showed that children with cancer were functioning better socially and emotionally, similarly, to case controls although children with cancer reported lower athletic self-concept. Teachers also rated the children with cancer as more sociable and less aggressive.

Successful school experiences are important in providing a sense of normalcy. The attainment of academic skills is believed to have positive implications for self-esteem, social relationships, and successful integration into later career roles as adults. To date there is no consensus about the long-term neuropsychological consequences of cancer treatments. Standardised measures have also failed to identify the subtle deficits in cognitive, academic and psychometric functioning that negatively impacts on educational progress. Bessell (2001) suggests that children with cancer have been found to be at risk for school adjustment difficulties for a number of reasons including increased absenteeism, changes in social interaction and school phobia. These factors make re-integration of children into school an important priority. Vance and Eiser (2002) reviewed literature to investigate school experiences such as school absence, behaviour problems and social relationships, of children with cancer upon returning to school. They

concluded that: (i) school absence is higher for children with cancer as compared to healthy children and those with other chronic conditions, although absence decreases over time, missing school is still a major concern for survivors; (ii) there is mixed evidence concerning significant behavioural problems at school; and (iii) studies involving social and peer relationships generally conclude that children with cancer are more sensitive and isolated than their peers, according to both peer and teacher reports.

Research conducted by Koch, Harter, Jakob and Siegrist (1996), found that a high weekly time load, long periods of inpatient treatment, frequent relapses and grave complications, a high rate of absence from school and/or repetition of school years, to be significant stressors for children with cancer. In the same study parents reported that their children were negatively affected by the lack of contact with other children, they had shown a tendency to brood, had difficulty concentrating and had problems with aggression and sleep disturbances. Noll, Bukowski, Rogosh, LeRoy and Kulkarni (in Kazak, 1992), compared teacher ratings of children with cancer with a matched sample of healthy peers and found that children with cancer were more isolated and perceived as having less leadership potential than their peers. While some peer relationships seem to suffer, relationships with other patients appeared positive and supportive. Van Dongen-Melman and Sanders-Woudstra (1986) investigated patient-patient relationships and found that those with similar medical conditions were seen to be a valuable source of information and were generally supportive and encouraging.

4.2.1 DEVELOPMENTAL STAGE AND ADJUSTMENT TO CANCER

Chronically ill children share most of the characteristics and developmental milestones and tasks of their healthy counterparts. The difference is that development is played out in a different context, where the child's special needs emanating from the medical condition interacts with the tasks often exacerbating the demand placed on parents. Theories relating to children have to therefore accommodate changes in understanding that occur over a period of time and take into consideration the developmental processes. Some theorists have argued that children's understanding of their illness mirror more

general changes over time. While others have argued that children's understanding of their illness is more idiosyncratic, reflecting their encounters with the disease and illness. The diagnosis and treatment of cancer may cause major interruptions in the life cycle hence optimal psychosocial development is a challenge. The literature suggests that failure to proceed with developmental processes (psychosocial, cognitive and sensory motor development) will lengthen and distort the process for the child. The threats to normal development posed by the cancer diagnosis are damage to the developing central nervous system, lack of opportunities to practice motor skills and interpersonal skills, lack of cognitive stimulation and separation and loss. Individual variables such as age, maturity, cognitive sophistication and stage of affective development, influence how children respond to cancer treatment. The current study was limited to children between the ages of 5 and 18 years, accordingly, the discussion which ensues will be limited to developmental issues pertaining to this group.

Early Childhood (3-5 years)

The thought processes of the child at this stage are sufficiently mature to seek explanations and to resolve certain problems. They are, however, unable to truly understand the complexities of the illness. A fundamental consideration in interpreting children's responses to medical settings in this age group is recognising that they see health and illness as two separate states and they generally assign responsibility of health to parents (or God) and responsibility for the illness to themselves. According to Bibace and Walsh (in Bennet, 2003), the first stage of understanding illness, corresponding to the Piagetian phase of pre-operational thought occurs between the ages of 5 and 7 years. Illness is conceptualised as a result of magic, witchcraft or as punishment for not obeying parental instructions: a phenomena known as imminent justice. They may see cancer as something bad, which they have caused and consequently treatment and restriction of their activities would be seen as punishment.

Rowland (1989) argues that because of the egocentricity associated with this stage the

child feels responsible for the illness and therefore feels acutely guilty about any changes, tensions or conflicts at home that s/he perceives to result from the illness or care. Physical restrictions and the loss of mobility affect the child's newly emerging sense of competence and control during this stage of development (Sourkes & Proulx, 2000). This stage is characterised by a shift from dependence to independence, illness and medical procedures place constraints on mastering autonomy, resulting in a display of negative reactions such as anger and forceful resistance. The child's efforts to regain control may lead to oppositional behaviours such as stubbornness and tantrums. Separation anxiety and regression are the most common responses to stress.

Middle childhood and latency (6-11 years)

By this stage the child has developed a repertoire of cognitive abilities that allow him/her to understand illness. Initially the child's view of the illness is global and concrete. It is tied to the immediacy of physiological functions and symptoms (Sourkes & Proulx, 2000). This stage corresponds to the concrete operational stage and is characterised not only by an increasing awareness of the disease and personal control, but also greater anxiety. Bibace and Walsh (Bennet, 2003), suggest that two stages of illness causality are reflected in this period: (i) the contamination stage during which the child defines illness in terms of multiple symptoms and views transmission as physical contact with a source (eg. germs and dirt); and, (ii) in the internalisation stage, the child continues to view the cause of illness to be external but begins to view illness as a result of internalising an external contaminant. An increasing sense of control leads to a larger repertoire of coping skills.

The experience of cancer for the school aged child is dominated by the effects of treatment and results in isolation from peers, school and normal activities. A study investigating the relationship between social support and adjustment by Varni, Katz, Colegrove and Dolgin (1994), reported that although children newly diagnosed with cancer, frequently fear re-entry into school, there is evidence that children aged 8-13 years, showed better psychosocial adjustment when they perceived that they were

supported by their peers. Hence, they recommend a prompt reintegration into the classroom. According to Rowland (1989), multiple absences from school and physical side effects of treatment (eg. fatigue, diminished attention and concentration, IQ loss secondary to tumours or treatment of the CNS) can compromise academic competence and self esteem.

Emotional reactions of children at this stage include: fluctuations in mood, feelings of being different, thoughts of death and manifestations of regressive behaviour. Enskar, Carlsson, Golsater, Hamrin and Kreuger (1997), found that pain, fear of pain and fear of the unknown constitute the most difficult aspects of hospitalisation. A diagnosis of cancer also threatens a child's increasing independence, autonomy and self-image and disrupts the establishment of relationships outside the family (Langton, 2000). Illness revolves around hospital visits, not being able to play with friends and the fear of getting hurt. Signs of distress may include regressive behaviour (clinging, tantrums and bedwetting), separation anxiety, depression, diminished self-esteem and school phobia. Bodily changes such as alopecia, amputations, skeletal abnormalities and weight gain or loss may be perceived as stigmas, which can potentiate decreased self-esteem and thus affect social and emotional adjustments (Van Dongen-Melman & Sanders-Woudstra, 1986).

Adolescence (12-18 years)

This stage corresponds to the formal operational thought phase; notions of health are more sophisticated, as the adolescent is capable of thinking more abstractly. According to the model proposed by Bibace and Walsh, adolescents have a sophisticated understanding of the physiological processes underlying the disease. Illness is seen as having multiple causes and, hence, multiple cures. The adolescent is not only able to comprehend the potential long and short term consequences of cancer but also the psychological sequelae. Enskar et al. (1997) assert that the child recognises the repercussions of the illness on his/her life as well as that of parents and siblings. Van Veldhuisen's (1991) clinical impressions with adolescents indicate that besides feelings of guilt arising from the conviction that they are responsible for the disease, they also have feelings of guilt about

the grief and difficulties, which they are causing their parents because of the illness.

Blumberg and colleagues (in Rowland, 1989), summarise the principal developmental tasks of adolescence as fourfold: to achieve a stable identity or self image; to adjust to an adult sex role and enter into mature relationships with peers of both sexes; to gain independence from the nuclear family unit; and to begin to prepare for the future by making an initial vocational choice. A cancer diagnosis makes attainment of these tasks challenging. Ostroff and Ross (2000) cite studies conducted by Bryne et al., 1989; Lansky et al., 1986; and Teta, et al., 1986; which found that childhood cancer survivors may experience delays in achieving normative developmental milestones such as leaving their parental home, getting married or obtaining full time employment, thereby supporting the above contention. After diagnosis adolescents describe a state of flux of emotions, including trying to find meaning (why me?), disbelief, depression, loneliness and aggressive behaviour. This state of flux covers a range of emotional experiences and exposes both their vulnerabilities and resilience. Ostroff et al., 1989; and Smith et al., 1991 (cited in Ostroff & Ross, 2000), in their studies found that adolescent cancer survivors experience both areas of vulnerability (eg. emotional distress, persistent intrusive thoughts about their illness and treatment, concerns about body image and dating) as well as resiliency (school achievement, social competence, positive self-concept).

Treatment schedules often revolve around hospitalisations, and severely disrupt schooling, socialising, the development of intimate relationships, and the achievement of independence. Koocher and O'Malley (1981) report that the negative impact of social isolation from a critical reference group is often compounded by the adolescent's need for increased dependence on his/her parents. A situation that threatens the drive toward emancipation and that may at times be as distressing to parents as it is to the adolescent. The adolescent has to cope not only with the normal physical changes (ie. maturing sexually and physically) that occur as a normal part of puberty, but also with the changes which occur in consequence of the disease and treatment. These effects often involve impairment in athletic ability and decreased physical attractiveness. Drug side effects such as acne, obesity and the characteristic 'moon face' that is part of steroid treatment

are readily visible and have a negative impact on the adolescent's self confidence and self-esteem.

4.2.2 CRITICISMS OF THE STAGE THEORY

There have been many criticisms levelled at the use of Piagetian theory to explain children's understanding of illness. Bird and Podmore (1990) questioned the methodology that Bibace and Walsh used and the validity of the model. Their criticisms of the Piaget stage theory are that he focused on how children think, know and understand at different stages and he paid little attention to the cultural or social environment. Vygotsky (1986) argued that it was impossible to understand development without recognising that it arises in specific social and cultural contexts that are an integral part of an individual child's intellectual growth and development.

In another study, Dimigen and Ferguson (cited in Bennet, 2003), failed to find a strong relationship between Piagetian stages and children's understanding of the nature of cancer. Other researchers Smith and Cowie, 1988; and Rushforth, 1996 (cited in Langton, 2000), contend that this theory underestimates the child's mental capacity. Their research has found that even very young children have the potential to develop a sophisticated understanding about their health and illness, and on the other hand, older children may regress in their ability to use abstract thinking because of their distress. Eiser (1989) found evidence of magical thinking not only in children but also in college students and adults, this led him to conclude that children's understanding of illness is better explained by the accumulated increases in knowledge than by a qualitative shift from one cognitive stage to another. In their quest to find other dimensions along which children identify illness, Goldman, Whitneysaltiel, Granger, and Rodin (1991), found that 4-6 year olds considered illness in terms of the causation, identity, consequences, probable duration and whether they were curable. These dimensions are similar to those used by adults and have been discussed in chapter 3.

4.2.3 ADJUSTMENT AND COPING WITH CANCER

Researchers have used different models to study coping with paediatric cancer. Within the context of the developmental model, age is used as a determinant of how the child copes. In contrast to the stress and coping model, this viewed and analysed coping strategies within the context of stressful situations. Irrespective of the model used, many studies of coping view the reactions of children who have cancer as normal responses to an abnormal situation. The emotional responses elicited by any situation are based on the result of information processing, and the outcome of the process of appraisal, which results in the perception of threat. Hence not all children with the same condition develop the same psychosocial problems. This suggests that moderating factors may have a role in determining the outcome. The stress of cancer poses a major challenge to any child's resources and abilities. Research in the field has found patient variables such as the nature and severity of the disease, the age at which the child is diagnosed with cancer and the time lapse since treatment completion, all have an influence on psychosocial adjustment. In general, patients who have an excellent prognosis for long-term survival (eg. early stage of cancer, certain types of cancer) and who receive treatment that is shorter in duration and less toxic, as evidenced by fewer side effects and less physical disability, report the least amount of psychosocial adjustment (Koocher & O'Malley, 1981; Spinetta & Deasy-Spinetta, 1981).

Control issues are of particular concern to adolescents as it relates to the confidence that they have in their ability to exercise influence over their own lives and their future. Compass, Banez, Malcarne, and Worsham (1991), concluded that a belief in personal agency acts as a moderator against stress. They found that by the age of 13 years children are able to understand contingency, competence and the possibility of controllable events. As children began to distinguish between truly controllable events and those where effort may be rewarded, coping methods became more appropriate. These cognitive achievements facilitated more realistic concerns eg. children worried about loss of friends, loss of abilities, relapse and loss of body parts.

Kellerman et al. (in Kameny & Bearison, 2002), studied locus of control of healthy and chronically ill adolescents. Adolescents with cancer exhibited a more external locus of control thereby attributing less control to them and placing more control in hands of fate and other external circumstances. The researchers concluded that an external locus of control is an accurate perception of reality rather than a deviant or poor form of adjustment. Nannis et al. (in Van Veldhuisen, & Last, 1991), found that a sample of adolescents with poor prognosis used illusory control to maintain a sense of control over their situation and reduce feelings of helplessness. They were more optimistic and hopeful than their physical condition allowed.

Kashani and Hakami (1982), conducted structured psychiatric interviews with both children (6-17 years) and their parents, and found that anger and irritation occurred frequently in over 50% of the children, even in children who survived cancer for many years. Theorists speculate that one explanation is that this is displaced anger which they feel towards medical personnel for inflicting pain and discomfort, evoked by the attribution of responsibility towards these people. Sourkes and Proulx (2000), suggest that another factor that provokes an anger response is the issue of protection. Each time the child encounters a new crisis or undergoes a painful procedure his/her sense of security is threatened as they feel that their parents were unable to protect them. These researchers also found an additional dimension in their study in which the child attempted to spare their parents the intensity of his/her fear and sadness. Parents took this cue and responded to their children in the same manner. This response had an adverse effect on psychosocial adjustment as it isolated the child and parents from each other at crucial times when mutual disclosure would have been comforting.

4.3 SYSTEMS MODEL

Kazak (2001), expanded upon the social ecological approach of Bronfenbrenner within the paediatric oncology field to explain the interactions among childhood illness and the individual and systems internal and external to the family. The ill child is located at the centre of a series of concentric circles with nested circles representing increasingly larger

environments with which the child interacts. Kazak (1992) describes the concentric rings around the child as follows:

- The *micro-system* represents the most immediate setting in the family. Thus family resources, interactions and adaptations in coping are the focus.
- The next ring is the *mesosystem*, which encompasses the interactive relationships in which the child participates, namely: schools, hospitals, neighbourhoods and agencies.
- The next ring is the *exosystem*, comprising of the parent's work environments, parental networks and schools attended by other siblings that do not involve the child directly.
- Most peripheral to the child is the *macrosystem*, which is characterised by the impact of culture and policy on children. At this level families are affected by public health policies and access to educational institutions as well as societal beliefs and stigmas, ethnic and racial diversity issues and insurability.

Interactions among people are characterised by their reciprocity eg. the child is not a passive recipient of unidirectional actions of other people and environments but rather an active contributor in multidimensional interactions (Kazak, 1992). This theory highlights the reciprocity and change in the course of development while simultaneously providing a framework that can guide family systems intervention that promotes competence and positive developmental outcomes.

4.3.1 THE FAMILY

Sourkes (2000) suggests that the family affords a refuge in which the child can replenish psychic resources and be shielded from the battering assault of the illness. The diagnosis of cancer in children generally requires a family to reorganise itself to be available on a flexible, unpredictable schedule and to provide unlimited quantities of support and reassurance to allay anxiety and deal with emotional pain. Thereby, demanding that the family develops creative means of integrating the sick child with its community and institutions and administering treatments and discipline. The family must develop

appropriate expectations for the child whose physical and emotional development deviates significantly from the norm (Librow, 1989). Traditionally the child's nuclear family (parents and siblings) constituted the core support system surrounded by the extended family (grandparents and other close relatives). This system can no longer be assumed to exist in most families in the current social context. The structure of the family has changed markedly to include; divorced and reconstituted/blended families, single parent families and children of parents in same sex unions. In South Africa, many children are cared for by alternate caregivers and not their parents. The main reasons for these practices are economically and socially based: the AIDS pandemic has resulted in a large population of orphans and orphan headed households, employment opportunities far away from home, schooling unavailable in some areas results in children boarding with friends and relatives, the previous injustices of the apartheid system (eg. the migrant labour system, the Group Areas Act and institutional inferior education). Who then constitutes the family (multiple generations, unrelated adults, related adults, common-law marriages, cohabiting partners, teenage siblings who substitute adults) especially when decisions pertaining to health care needs to be taken immediately?

Impact and coping

Futterman and Hoffman (cited in Koocher and O'Malley, 1981), suggest that successful coping involves accomplishing a number of specific tasks:

- maintaining confidence (a sense of parent's own worth, a sense of mastery and control);
- maintaining emotional/interpersonal equilibrium;
- reorganising their lives (integrating the experience of the child's illness and death into their personalities); and
- anticipatory mourning.

Each of these tasks involves elements of two aspects of coping: internal psychological protection of the person; and external mastery of the physical/social/ emotional reality. Protective strategies include: isolation of affect, increased motor activity, denying the

diagnosis or prognosis, avoiding visits to the child, seeking explanations for the development of the disease to avoid guilt, putting trust in the primary physician, avoiding discussions of death, and hostility towards medical staff. By contrast, coping behaviour includes: making practical, necessary arrangements for care and transportation, seeking medical information about the disease in an attempt to master it intellectually, allowing one to feel and express sorrow and grief, giving and using emotional support and talking openly about the illness. Koocher and O'Malley (1981), found that there are elements of both the internal/protective and external/mastery aspects of coping at all times in the course of treatment, but protective responses were stronger during the higher stress points such as diagnosis and relapse.

The disease and its treatment create a series of stresses or crises for the child, family and immediate social network. Lowenberg (in Koocher & O'Malley, 1986), suggested that the behaviour of parents of fatally ill children is governed by either an "approach" or "avoidance" orientation. Approach behaviour was aimed at mastery of a problem or a threat and avoidance behaviour, at escaping the stressful and threatening reality either through physical avoidance or cognitive distortion. The excessive use of defence mechanisms such as avoidance and denial, has the effect of distorting reality, which may eventually result in compromised care of the child and prevent the accomplishment of anticipatory mourning

Providing emotional support is one of the most abstract and compelling roles that the family has to assume upon diagnosis. Despite their own emotional responses, there is an expectation; often at both the overt and covert levels by medical staff, that the family should be able to contain their own feelings in order to provide support for the patient. The diagnosis of cancer in a child must be one of the most distressing life events that a family has to confront. It results in a frightening crisis to which each member responds in his/her own characteristic way. Langton (2000), reports that virtually no family is unchanged by the diagnosis and treatment as family plans and routines are disrupted.

The initial reaction of caregivers to a diagnosis of childhood cancer has been widely

researched and terms such as shock, anger, disbelief, numbness, and feeling stunned have been used to describe it. Although people are different and their response to devastating news will differ, many parents reacted to the diagnosis with anxiety, grief, depression, helplessness, hostility, and guilt. According to Faulkner, Peace and Keefe (1995), many respondents in their study did not realise that cancer could affect children and found it difficult to relate it to a child who had been previously healthy. They also found that parents who had no prior experience with cancer, reacted to the diagnosis with a sense of disbelief and horror. According to Hockenberry and Coody (in Langton, 2000), previous methods of coping will influence the family's initial reaction to the diagnosis and their ability to adjust, for example, experience of illness, cancer in the family/friends, past or concurrent stresses. These findings varied in a study by Faulkner, Peace and Keefe (1995), who found that for some parents the experience of relatives and friends who had cancer made it worse, while for others it made it better because they knew what to anticipate during the treatment phase.

Despite improved treatment regimens and better prognosis, the diagnosis of childhood cancer is still inextricably linked to death and seen by many as analogous to a grief reaction. Freud (1917), described mourning as a slow, gradual, painful process, in which there is a preoccupation with the lost person. This process requires much energy and while continues leaves the bereaved depleted of energy for other things such as; investment in other relationships, in life's tasks and life's pleasures. Koocher and O'Malley (1981), suggest that the process of anticipatory grief has been studied most comprehensively by Futterman and Hoffman, over a period of six years using a sample of parents of children diagnosed with leukaemia. They defined anticipatory grief as "a set of processes that are directly related to awareness of the impending loss, to its emotional impact and to the adaptive mechanisms whereby emotional attachment to a dying child is relinquished over time". Futterman and Hoffman have delineated five interwoven processes constituting parents' anticipatory mourning:

1. *acknowledgement*: true realisation that the child's death is inevitable;
2. *grieving*: the experience and expression of sadness and pain;

3. *reconciliation*: development of a perspective of the child's death which preserves a sense of worth of the child's life and of life in general;
4. *detachment*: withdrawal of emotional investment from the child as a growing being with a real future; and
5. *memorialisation*: development of a mental representation of the dying child which will endure beyond the child's death.

This process is believed to evolve through different stages and parallels a parents understanding of the child's life expectancy. The study found that anticipatory grief was an adaptive and necessary process that most parents were able to successfully accomplish.

While this would have been a viable theory, especially when the prognosis was poor, it raises particular difficulties with the emphasis shifting from imminent death to an uncertain future of living with a chronic life threatening illness. Easson (in Van Dongen-Melman & Sanders-Woudstra, 1986) reported that families who had adjusted to a future without their child had serious difficulties when the child survived cancer and often professional help was required to re-integrate the child into the family. It raises questions as to how parents (who have either mourned or partially mourned) cope with and respond to a child who has survived. Koocher and O'Malley (1981), report that parents respond by becoming over-protective and in consequence, children show clinical signs, separation difficulties, infantilisation and hypochondriasis. Not all parents responded in this manner, studies have shown when children are doing well medically, the threat of loss becomes remote and parents move from a state of anticipatory mourning to increased hope and cure (Van Dongen-Melman & Sanders-Woudstra, 1986).

When the child responds well to treatment and impending death is not considered to be a primary stress, parents move from a state of anticipatory mourning to an increased hope for cure. A study by Kupst et al. (in Van Dongen-Melman & Sanders-Woudstra, 1986), reported that with continued remission, affirmation of life becomes stronger and most parents experienced few difficulties and returned to normal life. However, when the child relapses parents move back into the anticipatory mourning phase. The relapse experience

is often worse than the initial diagnosis. Koocher and O'Malley (1981), reported that the pattern of remission and relapse in the course of childhood leukaemia can cause special emotional difficulties for parents, who respond to remission either with a great deal of renewed hope or with doubts that the original diagnosis could possibly have been correct. When relapses occur hopes are smashed and painful grief is renewed. Friedman suggests that while parents continue to hope, their hope narrows with the progression of the disease, finally converging on living from day-to-day (Van Dongen-Melman & Sanders-Woustra, 1986).

As the shock and disbelief dissipates and an awareness of the intensity of the disease becomes apparent, anger and guilt may ensue. Although the cause cannot be specifically attributed to any particular source, there is a need to apportion blame to someone or something. This allows anger to be directed somewhere and can therefore serve as a temporary attribution of guilt. Pinkerton (in Langton, 2000), found that parents expressed anger at the hospital doctors who confirmed the diagnosis, or at God for allowing it to happen, or at the disease itself for the disruption and distress it causes. Doctors and nursing staff are also considered to be the ones who inflict pain and are perceived to be the instigators of the treatment, which makes the child, feel very ill. Parents also direct anger at themselves for the occurrence of the disease and see themselves as having failed to respond to the child's complaints of ill health seriously and promptly (Faulkner et al., 1995). Although some degree of anger, injustice and unfairness is normal, prolonged anger can be destructive when maximum support from others is required. It also does not help the child cope with the illness and treatment (Ekert, in Langton, 2000).

People generally feel confident, competent, secure and powerful in situations in wherein they can exercise a measure of control. Conversely, when a situation is perceived to be beyond one's control, it usually creates anxiety and fear and one responds with helplessness and depression. Childhood cancer is dominated by uncontrollability for parents, as the disease and treatment processes are unpredictable and without clearly defined stages. Studies conducted by Maguire et al., 1979; Natterson and Knudson, 1960; and Powerzek et al., 1980 (cited in Van Dongen-Melman & Sanders-Woudstra, 1986)

confirmed that anxiety and depression occurs in 50% of the parents although most of these symptoms subside or spontaneously disappear during treatment.

Van Veldhuisen and Last (1991), contend that numerous uncertainties occur: prior to the diagnosis there is the uncertainty as to whether the suspicion will be confirmed; after the diagnosis there is the uncertainty of prognosis, the length and severity of treatment, the length and the number of hospitalisations, the side effects of therapy on the wellbeing and development of the child, the complications which could arise and the test results which could indicate remission or relapse. Parents experience fear and uncertainty as they realise that anything can happen. The anticipated threat of a fatal outcome hangs above their head like a 'sword of Damocles' (Koocher & O'Malley, 1981). A study by Clarke-Steffen (cited in Langton, 2000), found that helplessness arose from a feeling that they were unable, for the first time, to do much to help or protect their child.

Due to the life-threatening nature of childhood cancer, it has been conceptualised within the posttraumatic stress disorder (PTSD) model. Kazak (2001) advocates that the diagnosis and treatment evoke responses similar to that of children and families experiencing other types of trauma (helplessness, horror, physiological arousal, reminders, intrusive thoughts), additionally, the threat of death persists throughout the course of treatment and even after treatment ends. Research on the impact of childhood cancer on the family has focused on the prevalence of PTSD or posttraumatic stress symptoms (PTSS) in parents. Research conducted by Barakat, Kazak, et al., 1997 (in Kazak, 2001), found that both parents are affected by the diagnosis and parents of childhood cancer survivors have higher rates of PTSD/PTSS than parents of healthy children. The same group of researchers in a later study (2000) concluded that higher levels of PTSD found in mothers of cancer survivors were related to long term adjustment difficulties.

Each parent has his/her own strengths and weaknesses resulting in a wide variation of coping behaviours which results in corresponding family difficulties or resilience. Because of their close involvement in the coping processes of the sick child parental

opportunities for personal development are also affected. Petermann et al., 1987; Quittner, 1992; and, Noeker and Petermann, 1995 (cited in Koch, Harter, Jakob, & Siegrist, 1996), suggest that the main stressors on parents are:

- Additional financial burdens, problems in holiday planning, restrictions on free time, (temporary) relinquishment of employment/profession, rethinking of professional career plans.
- Hospital admittances, treatments, appointments and bureaucracy.
- New definition of intra-familial roles, responsibility for serious decisions on therapy.
- Emotional problems in the acceptance of the disease and its chronicity, anxiety in the face of risks of life-threatening sickness, fear of separation, of loss and of death.

As a consequence of these manifold pressures, the parents and family as a whole may experience emotional, behavioural and social problems as well as partnership conflicts, anxiety, depression and psychosomatic disturbances.

The presence of cancer in a child also brings the coping styles of both parents into sharp focus. The literature base on the emotional reactions of parents to childhood cancer reveals differences in emotional responses between mothers and fathers. Van Veldhuisen and Last (1991) reported that various studies: Kupst and Schulman, 1980; and Magni et al., 1983, found higher levels of depression in mothers while fathers scored lower on all levels of distress and higher on the anger scales; Marky, 1982, observed that during the child's treatment, mothers showed more psychosomatic complaints than fathers; and a study by Rando, 1983, deduced that fathers were inclined to accept the situation more easily. Another study conducted by Faulkner et al. (1995), found that some husbands and wives had difficulty talking to each other, fathers in particular had difficulty talking about their feelings and the retrospective group of fathers were found to have suppressed their grief for 2-11 years and were only able to express it when given permission to through the research interview. Ekert (cited in Langton, 2000), concluded that pre-existing stresses were exacerbated and subconscious feelings of anger and resentment by one or other parent resurfaced and caused a rift in the family.

Reay, Bignold, Ball and Cribb (1998) argue that the gender dynamics that develop are the consequences of a complex mixture of external constraints and internal inclinations. There are two reasons why women bear the bulk of the physical and emotional onus of coping with cancer. Firstly, women have traditionally carried the overwhelming responsibility of physical and emotional care giving in families. Caring is socially constructed as an area of female competence. Secondly, the practicalities of fitting childhood cancer into family life results in the women giving up paid employment, domestic responsibilities or both, to take care of the sick child, while men continue to work in order to meet the family's financial commitments.

Koch, Jakob and Siegrist (1996), studied 504 families and confirmed that a comparison of the stressors and coping behaviour of mothers and fathers showed some gender-specific characteristics. The distribution of tasks and responsibilities between parents followed two patterns: in one group of families the mother carried both the burden and responsibility either exclusively or predominantly; in another group an equal distribution was observed. In 10% of their sample other family members such as grandparents were also centrally involved in caring for the sick child. An exclusive or dominant assumption of responsibility by the father was the exception. Similarly with parental employment, they found that the relinquishment or loss of employment among fathers was an exception. One third of the mothers felt it necessary to give up their work either partially or totally, whilst 11% lost their employment and a further third had to change their hours of work or forego further qualifications or a better paid position.

Cook (cited in Van Veldhuisen & Last, 1991), attributes these gender differences to social roles which fathers and mothers assume, which entail differences in problem orientation: mothers are intensely involved in caring for the sick child, while fathers orient themselves more to tasks which will guarantee the economic continuity of the family. The differences in task orientation influence the appraisal process and thus explain the different emotional responses. Reay et al. (1998) studied the gender dynamics of 35 families coping with childhood cancer. They found that women's coping mechanisms involved a close-up emotional engagement with cancer, while, fathers on the

other hand tended to distance themselves emotionally from the illness resulting in a reluctance to talk, the playing down of the diagnosis and an unrealistic overly optimistic stance. Men appeared to be operating with a disjuncture between feelings and the communication of feelings which over time led to increasing stress and illness in them. The study found that fathers developed a wide range of physical ailments (ulcerative colitis, thyroid problems, diabetes and Parkinson's disease) in the period following their child's treatment.

The literature has a tendency to characterise a parent's adaptation to their child's cancer in terms of the deficit model, as 'maladaptive', but does not focus adequately on how parents live with their child's illness and the kinds of difficulties they encounter in their interaction with health services. Dixon-Woods and Heney (2002), recommend that "parenting a child with cancer needs to be re-characterised to draw attention to how parents' identities and social obligations position them in relation to the medical world, to highlight the emotional work carried out by parents and to show how becoming and being a parent of a child with cancer invites surveillance of parenthood". After diagnosis, parents are forced to make a striking biographical transition, which necessitates a re-definition of their identities to incorporate a non- normative dimension into the family life cycle.

Research conducted by Young et al. (cited in Dixon-Woods et al. 2002), examined mothers' experiences of childhood cancer, and concluded that although some aspects of mothers' self-identities are indeed challenged, changed and even undermined by their experience of caring for a sick child, their identities as mothers, established long before their child's illness is unlikely to be subsumed by, or lost to, their caring role. The researchers surmised that the experience of being a parent (particularly a mother) of a child with cancer is most appropriately represented as an intensification of the existing role of parents rather than an adoption or extension of the role of carer.

Cancer in a child affects both parents and they need each other in order to cope with this event. Hence, the quality of the marital relationship before the diagnosis is an important

factor in determining how parents will adjust to the crisis together. Families with pre-existing marital problems are likely to struggle with the support needs of their partners due to an already compromised structure. Early studies conducted during the era when prognosis was poor, using the deficit perspective, suggested that stressful situations are assumed to create disruption in the family social system. But the recent trend in adopting the family stress theory resulted in a shift towards understanding resiliency and growth in families experiencing stress.

Studies of marital relationships among parents of children with cancer have yielded mixed and conflicting results. Lavee and Mey-Dan (2003) highlight these mixed findings by citing the work of some researchers: Cornman (1993); and Fife, Norton and Groom (1987), found that the marriages of parents of children with cancer to be more distressed than established population norms or comparison groups, whereas others such as; Wittrock, Larson and Sandgren, (1994), found no difference in marital adjustment between parents of children with cancer and parents of children with more common illnesses, such as influenza. Barbarin, Hughes and Chesler (1985), using interviews and observations found that marital satisfaction remained either unchanged or even increased and that family cohesion was strengthened by experiences with childhood cancer.

Studies of marital quality among parents of children with cancer focus on positive and negative changes in the relationship. Lavee and Mey-Dan (2003) studied 35 couples to assess their perceptions of change, namely; whether relationships changed equally across various aspects of the relationship; and whether change in the relationship varied across years of the child's illness. They found that sexual relationships were most negatively affected, while marital communication was significantly improved (as a result of sharing intense emotions, taking on the joint responsibilities and providing mutual support), resulting in a more positive attitude towards a spouse. The deterioration in sexual intimacy may be accounted for by the tremendous investment in physical and emotional energy that leaves parents with less time and energy for leisure activities as well as a depressed mood and long periods of feeling too drained for sex. This restriction of intimacy was also confirmed in an earlier study by Maguire (1983), who studied mothers

of children with leukaemia and found that 20% of his sample had no sexual contact with their partner since their child's diagnosis or did not experience pleasure from it anymore. The pattern of change in marital relationships across time indicates a greater deterioration in the marital relationship during the first year and in cases of long-term illness (4 or more years) compared with a more positive change in the relationship among parents whose children had been ill for 2 or 3 years (Lavee & Mey-Dan, 2003). Lavee and Mey-Dan (2003), explain this form of change in two ways. First, it reflects phases of the illness and the child's condition: during the diagnosis and hospitalisation periods are highly distressed and the marriage is greatly affected but when active treatment ends and the child goes into remission the family returns to normality. However if the child relapses or requires additional hospitalisations, it again takes its toll on the marriage. Secondly, the pattern of change in marital relationships over time follows the 'general adaptation syndrome' and the ABCX models. This curvilinear pattern of change reflects an initial crisis reaction which disturbs established patterns of relating, with the passage of time, homeostasis is re-established and the couple learns new patterns of communication, conflict resolution, parenting and family roles. If, however, the illness continues, resources are depleted and the prolonged state of heightened stress gradually leads to a 'state of exhaustion' with impaired functioning, intensified personal strain and overall deterioration in the relationship (Lavee & Mey-Dan, 2003).

The type of appraisals made by the family following the diagnosis of childhood cancer, also determines their adaptation and adjustment. McCubbin, Balling, Possin, Friedrich, and Bryne (2002), studied 42 parents of children diagnosed with cancer, in an attempt to identify family resiliency factors that lead to positive adjustment. They defined as resiliency as "the positive behavioural patterns and functional competencies individuals and the family unit demonstrate under stressful or adverse circumstances, which determines the family's ability to recover by maintaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and the family unit as a whole" (McCubbin et al., 2002). Their study confirmed that the diagnosis thrust families immediately into a crisis situation; parents described feelings of shock, disbelief, unreality and being overwhelmed by information about the type of cancer and treatment.

They also identified six resiliency factors that helped families to recover from adversity:

1. Internal family strengths of rapid mobilisation and reorganisation. Families are tasked with establishing new patterns of functioning; roles, responsibilities and living arrangements have to be rearranged. This involved one parent's willingness to stay at home (and be separated from the other parent and child in hospital) and assume responsibilities for sibling care and household maintenance while still maintaining full time employment. Hence, the ability of the family to tolerate and manage separate living arrangements was crucial. In addition, each parent's emotional availability and affirmation of the other's contribution was important,
2. Support from the health care team. The second resiliency factor which was endorsed by 88% of the sample, was the support received from the oncology team in the form of reassurance and realistic hope, ready accessibility to information and assistance and respect.
3. Support from extended family. Eighty percent of the sample endorsed the importance of the extended family's assistance: parental respite, sibling care, transportation, emotional and instrumental support. Extended family support was crucial for single parents.
4. Support from the community. Empathy and support initiated by friends, neighbours, members of religious bodies and the community at large, which encompassed child care, financial aid, home maintenance assistance and emotional support.
5. Support from the workplace. This took the form of flexible work schedules, time off to be with the child and job assurance.
6. Changes in family appraisal. These parents revealed a pattern of finding new meaning to the changes in their lives created by a child having cancer. Their appraisal led them to understand their trauma and move forward.

Parenting and child rearing

Van Dongen-Melman and Sanders-Woudstra (1986), contend that parents' emotional

reaction to the life-threatening nature of the disease influences their attitude to parenting. Cancer places extraordinary challenges on parenting and child rearing which includes: talking to the child about the disease; supporting the child; taking care of the child's physical and emotional condition; and preparing the child for death as well as living. On the basis of their clinical experience, Dolgin and Phipps (1996), suggest that among the family processes that might be affected by the diagnosis of childhood cancer are the specific strategies and child rearing practices employed by parents in managing their children's behaviour and in meeting their emotional needs. Parents experience difficulty in exercising appropriate discipline and setting reasonable limits on the sick child's (and in some instances the well child's) behaviour.

According to Koocher and O'Malley (1981), over indulgence and over generosity, lead to behaviour problems in the sick child and aggravates sibling jealousy, whilst overprotection fosters regression and undermines the patient's effort at control and mastery. The over protective behaviour exhibited by parents, is suggested hypothetically to be a reaction to the fear of losing a child as well as feelings of guilt at not being able to protect the child from the cancer. These deviations from normal child rearing practices may also significantly alter the social development of these children.

Parents may play a significant role in determining how children cope with medically related fears and adjust to their illness, treatment and hospitalisation. Studies have demonstrated that parental use of positive reinforcement, modelling and reassurance correlated strongly with lower levels of anxiety amongst children, in contrast to the use of force or threat of punishment, which was associated with higher levels of anxiety. Dolgin and Katz (1988) demonstrated this in a study comparing paediatric cancer patients experiencing nausea and vomiting prior to the administration of chemotherapy to a group of patients matched for age and chemotherapy regimen but with no history of anticipatory nausea and vomiting. Parents of children with anticipatory nausea and vomiting reported employing the threat of punishment as a strategy of choice more, while parents of children who did not have anticipatory nausea and vomiting used modelling and reassurance more frequently. Dolgin and Katz (1988) concluded that the development of

anticipated nausea and vomiting in children depends on whether the parent's response serves to increase the child's anxiety and the likelihood of aversive conditioning (threat of punishment) or reduces it (modelling and reassurance).

Compliance to therapeutic regimens is also influenced by the child-parent relationship and interactional patterns, which occur in the family. Katz et al. (in Dolgin & Phipps, 1996) conducted in-depth interviews with adolescent cancer patients who were non compliant with treatment and described the family's role in facilitating or hindering compliance, in terms of patterns of over-involvement, under-involvement, and ambivalence. Parental over-involvement and protectiveness was found to be a barrier to patient-physician communication and trust, thereby sabotaging the therapeutic alliance resulting in a refusal of necessary procedures, missed appointments, and non adherence to medical recommendations. Parental under-involvement was manifested by children being inadequately supported while attending treatment appointments, resulting in unbearable stress trying to cope with complex medical systems. Finally, parental ambivalence regarding treatment may translate into poor patient compliance, particularly when the patient is also marginally motivated to comply.

Pre-existent roles and relationships within the family are altered drastically in the face of childhood cancer. This takes the form of an intensification of the relationship between the sick child and parents (especially the mother), to the exclusion of healthy siblings. Sourkes and Proulx (2000) found that when the sick child wields too much power, a complicated tangle of dysfunction can result; the marital dyad is disrupted and the siblings lose their visibility in the family.

4.3.2 SIBLINGS OF THE CHILD WITH CANCER

Murray (1998) conducted an extensive review of literature relating to the experiences of well siblings and of children diagnosed with cancer and concluded that the cancer experience is a stressor that may increase subjective feelings of stress by well siblings and in some cases lead to decreased psychosocial competencies and increased

psychopathologies. Children differ fundamentally from one developmental period to the next and just as developmental aspects of each age group dictate the particular challenges, stresses and risks for the child with cancer, the impact of the illness will also be dependent on similar considerations for siblings. An understanding of the concepts of 'illness' and 'mortality' gradually develop through childhood, hence, the child's level of understanding of what is happening in the family and his/her ability to rationalise it depends on the cognitive maturity of the child. Bendor (cited in Langton, 2000), studied a group of siblings of cancer patients aged 8-14 years and concluded that: 'a sense of danger, damage and possible death was ever present in the well siblings' lives'. It is also common for siblings to consider their own vulnerability to cancer.

Siblings have to adjust to a multitude of changes in their lives: bewilderment and disbelief at the diagnosis, disruption in life style and living arrangements, temporary separation from ill child and parent/s during the hospitalisation period and fears and fantasies as parents become preoccupied with the ill child. Changes which occur in parental roles and responsibilities alter sibling roles in that they may have to take on additional responsibility, for example; preparing meals and supervising younger family members. Healthy siblings have been identified as the most emotionally disregarded and distressed of all the family members when serious childhood illnesses affect the family (Spinetta, 1981; and Chesler & Barbarin, 1987). Murray (1998, 1999) asserts that clinical studies suggest that siblings are particularly susceptible to adjustment difficulties (depression, anger, anxiety, feelings of guilt, fear of death, feelings of loneliness, jealousy, resentment, and social isolation) and they experience stress similar to that of the ill child.

Spinetta (1981) found that the impact of cancer was worse for siblings than sufferers. Those conclusions were based on a 3 year longitudinal study of 102 siblings. The results showed that the emotional needs of siblings were met at a significantly low level: siblings between the ages of four and six had significantly lower self concept scores and a more negative attitude towards the self; while siblings between the ages of six and twelve years had more maladaptive levels of anxiety, depression, and acting out behaviours.

Sloper (2000) assessed the experiences and support needs in a sample of 94 siblings of cancer sufferers at 6 and 18 months after diagnosis. The results of this study revealed that 6 months after diagnosis, siblings reported a number of problems such as loss of attention and status; loss of their own and their families' usual activities (social life and leisure) and routines; loss of certainty and security; and loss of companionship of the ill child. For many siblings, problems had resolved 18 months after diagnosis, but problems persisted for others. Sloper (2000) found that not all siblings reacted negatively to these losses; some showed an ability to reflect on and understand their sibling's cancer and the change in their life circumstances. The cancer experience also had a few positive effects, including increased sensitivity and empathy for the patient and others, enhanced personal maturation and an increased appreciation for life and family cohesion.

Coping difficulties experienced by siblings could be attributed to a number of factors: the degree of disruption of family life due to illness; the coping resources available to the family; and siblings' perception of negative interpersonal effects on their lives. In 1996 Wang and Martinson (cited in Murray, 2000), examined the circumstances that were thought to contribute to the presence or absence of behavioural problems of healthy siblings in Taiwan. The data revealed that the major stressors were: insufficient knowledge; diminished family communication patterns; and unsatisfactory support. These researchers found that healthy Chinese siblings showed significantly greater behaviour problems and fewer social competence skills than a standardised normal Western population.

4.3.3 SOCIAL SUPPORT

Social support was initially defined according to the number of friends available to an individual. In recent years these definitions have been expanded to include not only the number of people providing the support, but also satisfaction with the support. Bloom (2000) defines social support as the degree to which an individual's needs for affection, approval, belonging and security are met by others. Cohen and Wills (1985) suggest that social support performs four functions:

1. *Esteem support*, other people increase one's own self esteem, it performs the function of letting people know that they are loved and accepted despite their shortcomings,
2. *Informational support*, whereby other people are available to advise on how to understand or cope with what is happening,
3. *Social companionship*, which involves spending time with others in recreational or leisure activities with the purpose of, either distracting them from their troubles, or facilitating positive moods, and
4. *Instrumental support*, which involves concrete assistance in the form of financial aid, needed services or material resources.

Cohen and Wills (1985) developed two theories to explain the role of social support in health status:

1. The *main effect hypothesis*, which suggests that social support mediates the stress-illness link with its presence, reducing the effect of the stressor and its absence, itself acting as a stressor, hence social support has effects independent of stress. According to this hypothesis, being a member of a large social network can provide a person with positive experiences (eg. positive affect, sense of belonging, self-esteem) and a set of ongoing socially rewarding roles in the community.
2. The *stress buffering hypothesis*, suggests that when a person is experiencing stress, the support of other people provides resources for dealing with the situation and hence 'buffers' the person against the possible ill effects. Social support also influences the appraisal of the potential stressor and enables the individual to select an appropriate coping strategy by comparing themselves with others.

The support needs are not the same for all parents even though their children carry the same diagnosis. People have different needs for support, which also depend on the severity of the stressor, personality traits, coping styles and quality of relationships with people in their network. Some people require a lot of support, while others are content

with less. There are also people who prefer to solve the problem on their own. Hoekstra-Weebers, Heuvel, Bosveld, and Kamps (1996), assert that the limited number of studies in the field of psychosocial paediatric oncology indicates that: social support was at its highest shortly after diagnosis and 6 months later, thereby effectively buffering the effects of diagnosis. The availability of emotional, informational and instrumental support has a positive effect on the adjustment of the parents and the child during and after hospital treatment. Distress in parents was found to be higher when there was a lack of emotional support, however, parents social companionship needs were not adequately met.

This lack of social companionship may result from parents being so consumed with the demands of the treatment phase that they lack the time or energy for social engagements. Greater interaction with people in the social network may also raise the likelihood of communication problems, criticism or unwanted advice (Hoekstra-Weebers et al, 1996). Koocher and O'Malley (1981) also found that social isolation was a problem faced by parents. This isolation was caused by a number of factors: such as myths related to cancer and the fear of contagion; discomfort and pain in the face of the threat of death; and, a feeling that they (friends) would be unhelpful in the face of an overwhelming problem. Chesler and Barbarin (1987) indicated that because of the possible stigmatisation and the need for privacy, many parents were reluctant to disclose the nature of their child's illness to friends, which resulted in feelings of helplessness and more isolation.

A major source of emotional support is derived from relationships with other parents of children with cancer. These relationships are based on shared problems and mutual understanding. Hence, satisfaction with support is an important concept in relation to psychological well being/distress. The roles which the primary support base assumes may vary depending upon the phase of treatment. Once active treatment ends, the supportive interactions of the medical team (oncologists, nurses, social workers, psychologists, etc), that was available during treatment, decreases. Bloom (2000), asserts that follow up visits to the oncologist actually become sources of anxiety and distress as each test could potentially reveal disease recurrence.

4.4 COMMUNICATION ABOUT THE DISEASE

The lives of people living with childhood cancer, was dominated by uncertainty and uncontrollability. In an effort to avoid being overwhelmed and overpowered, children and families have to apply coping strategies to reduce the uncertainty and uncontrollability. Uncontrollability and uncertainty are integral components of the situational meaning structure and influence the quality and intensity of the emotional behaviour, including anxiety, grief, despair and depression. Communication is thus an important vehicle through which people develop an understanding of and express emotions about the disease. Van Veldhuizen and Last (1991), suggest that the function of communication is the development, maintenance or alteration of the appraisal which forms the basis of emotions.

Communication about the disease is an important device for the child and parents. In their search for meaning and control, communication serves as a means of the appraising the situation. Open communication about the disease, diagnosis, treatment and prognosis enables children and their parents to assess the harm and threat posed by cancer, define the problem and attempt to solve it, thereby promoting primary control and problem-focused coping. Communication about the disease directed at secondary control of the situation (ie. coping ability, resources and the adequacy of resources to meet the harm and threat of cancer) promotes understanding and acceptance of the disease and aims to reduce negative emotions and strengthen positive emotions. On the one hand, the function of communication is to develop, maintain or alter the appraisal; on the other appraisal determines communication (Van Veldhuizen & Last, 1991).

Historically communication about disease and illness was solely the domain of the physician, who made the decision whether and to whom to reveal the diagnosis. This paternalistic model deprived patients the opportunity of active involvement in the decision making process that was consistent with their circumstances and reality (determined in part by their gender, race, socio-economic status, family dynamics and personality style). A number of changes have taken place over the last 20 to 30 years

resulting in a shift in attitude, culminating in policies that has entrenched patients' rights to medical information.

Divergent views characterised the early literature on whether the cancer diagnosis, treatment and prognosis should have been disclosed by doctors to patients and their families. Two approaches were advocated: namely; the open approach and the protective approach. The protective approach pretended that nothing was wrong, thereby protecting the child as much as possible from the enormity of the disease. The open approach adopted the contrary position and divulged all the details of the disease to the child.

Van Dongen-Melman and Saunders-Woustra (1986), contend that the advocates (Anthony, 1940; Koocher, 1973; White, Elson, & Prawat, 1978) of the protective approach base their contentions on the body of literature, which proposes that there is a developmental trend in the child's understanding of death. Share (in Koocher & O'Malley, 1981), suggested that children under the age of 5 years do not understand either the permanence or the universality of death, at that stage they see it as reversible and akin to separation. In middle childhood (6 to 9 years) death is usually understood as an external process involving physical harm and often as a punishment for wrongdoing. It is only from 10 years onwards that children attain a more sophisticated understanding of death as an internal process involving the cessation of bodily functions, which is permanent and inevitable.

According to Share, 1972 (in Koocher & O'Malley, 1981), the proponents of the protective approach have based their stance on three rationales. Firstly, the idea that children under 10 years are not capable of a real understanding of death and do not experience anxiety about death. Hence, children will not worry about dying unless knowledge of the true nature of their illness is forced upon them. By confronting the child with his/her potential death, fearful fantasies associated with the child's developing concepts of death may be activated and intensified: death, as punishment for bad thoughts and deeds or as abandonment. Secondly, they argue that children do not want or need much information about their disease and should not be given more information than they

request. This was based on the inference that children seldom ask questions about their illness. Thirdly, the assumption exists that the child's immature ego defences are inadequate to deal with the distress and anxiety which knowledge of the fatal prognosis will entail.

Koocher and O'Malley (1981), summarise the arguments challenging the wisdom and efficacy of the protective approach, giving rise to support for adopting the open approach. The first argument is that research on healthy children's concept of death is not wholly relevant to fatally ill children because even very young children who are dying experience a great deal of fear about the seriousness of their illness. Vernick and Karon (in Van Dongen-Melman & Saunders-Woudstra, 1986), argue that trying to shield the child from the seriousness of the disease results in feeding the unrealistic fantasies of the child causing depression, withdrawal and heightened anxiety.

Mc Intosh (in Van Veldhuizen & Last, 1991) observed that cancer patients who were not informed of their condition continuously scanned their environment for cues indicating threatening danger. They searched for significance in remarks or attitudes of the doctor. The significance of certain procedures or treatments, and compared their condition and treatment to those of other patients who presumably had the same or a similar disease. Secondly, the observed passivity and lack of questioning about death simply indicated that an adult's discomfort and silence made it difficult for children to raise the issue. Due to misconceptions about the child's awareness of death, the adult tended to remain silent, thereby overtly or covertly giving cues to the child not to talk about death. Karon and Vernick (in Van Veldhuizen & Last, 1991), defined this situation as a 'conspiracy of silence'. Thirdly, since children do experience and cope with a great deal of anxiety about illness, there is no reason to believe that their coping skills are inadequate and there is evidence which suggests that discussing fears and fantasies about death can be supportive of good coping.

In recent years most professionals who treat childhood cancer have opted for the open approach, due mainly to an acknowledgement that it is virtually impossible to protect

children from the awareness of their illness and its seriousness. The conceptual shift from paternalism to the 'shared decision making' model facilitated a relationship centred approach characterised by open communication and active participation and information exchange between the physician and the patients (and their family). Blanchard, Albrecht and Ruckdeschel (2000), suggest that the key is the negotiation between the physician and the patient as the physician obtains information and asks questions sensitive to the patient's social context so that patient preferences for the degree of information and participation in decision-making can be ascertained. Spinetta (1988) advances a convincing case against a number of objections raised by opponents of the open approach. He contends that talking to the child about the diagnosis and prognosis of cancer does not mean that the child is being told something new, but, instead, provides the child with opportunities to talk about his/her concerns and worries. If the child is unable to share suspicions with others, s/he can become isolated, depressed and dejected. According to Spinetta (1988) open communication reduces feelings of isolation and despair and promotes positive self-esteem.

The debate has now shifted from whether to tell, to how to tell. Buckman (in Papaikonomou, 2001), asserts that insensitive truth telling is as deleterious in its own way as insensitive truth concealment. Vernick and Karon (in Koocher & MacDonald, 1992), have argued that openness allows the child to feel more secure and trusting of the medical staff and parents, noting that 'blows cannot always be softened, but by explanation and sharing, their impact may be made somewhat less concentrated and acute'. Open communication amongst the child, medical staff and family has been recommended for the past 20 years or so, with the caution that it may not be appropriate in every circumstance or every culture or at every age level (Kameny & Bearison, 2002).

4.5 BELIEFS AND MEANING OF ILLNESS

Health and illness manifest at opposite ends of the continuum. Kleinman (in Die-Trill, 2000), suggests that the quality of life in the context of health and sickness is directly associated with individual meanings attached to the experience of illness. Hence,

irrespective of what cancer means to the patient and his/her family and how those beliefs develop, they will influence the psychological response to the illness and its treatment and will alter the person's interpersonal relationships and may influence adjustment to the medical experience. Gochman (1992) defines health cognitions as beliefs, expectations, perceptions, values, motives and attitudes that provide frames of reference for organising and evaluating health, regardless of whether those cognitions have demonstrable empirical linkages with health status and regardless of whether they are objectively valid.

Various factors influence the development of beliefs about cancer: the individual's age; sex; personal and familial experience with cancer; socio-economic status; educational level; cultural and religious background; health and illness related beliefs; social milieu (interpersonal relationships, employers and mass media); site and extent of the disease; time since diagnosis; type of treatment administered; knowledge about cancer and events that take place during the individual's and family's lifetime (Die-Trill, 2000). A study by Arpin, Fitch, Browne and Corey (1990) found that unfavourable cancer meanings contributed more strongly to distress and poor adjustment to illness, than disease severity and socioeconomic status. Beliefs and expectations about cancer are often characterised by defeat, despair, hopelessness, fear and superstition. These powerful negative images of the disease are frequently held by both healthy and ill individuals. In the twentieth century cancer has been used as a metaphor for evil (eg., in the media, crime and violence have been described as a cancer). Faulkner (1995) notes that the media tends to reinforce the negative message of cancer, and society's attitude to cancer is often characterised by prejudice, stigma, a sense of helplessness and possibly phobia. These attitudes can influence how a family copes with the diagnosis and how people behave towards them.

Initially, beliefs about the causation of illness was studied within the context of Kelley's (1971), attribution theory, which proposes that negative or unexpected events challenge one's sense of meaning, thus people search for reasons for these events. Causal attributions may be important ways of understanding people's response to and adjustment to cancer. Die-Trill (2000) cites studies by: Taylor et al. (1984); and Michela and Wood (1986), which have demonstrated that the process of attributing causes occurs in

individuals with serious illness as an initial attempt at gaining some control over their lives. Causal attributions have also been studied within the framework of Seligman's (1975), learned helplessness theory. Both these theories contend that that loss of control can contribute to the development of feelings of anxiety, depression and withdrawal.

Despite the aetiology of childhood cancer being unclear, many parents form theories about the origin of the illness. Langton (2000), asserts that there is evidence that parents of children diagnosed with cancer adopt a similar process to that of adults carrying the diagnosis; viz. the search for the meaning of illness is a basic spiritual need, an attempt to enhance their self-esteem and is a way of finding hope and purpose and gaining mastery over the complex and unfamiliar information. Ruccione et al. (in Langton, 2000) found that in answer to the question about anything that could have caused or contributed to their child's illness, parents mentioned environmental and family factors, parental self-blame and myths and misconceptions.

The relationship between causal attributions and psychosocial adjustment to illness is inconclusive and suggests that causal thinking may facilitate adjustment to cancer in some cases and may not have any effect on the illness experience in others or may even have a negative influence on some individuals. Research by Taylor, Lichtman and Wood (1984), did not support the assumption that adjustment is adversely affected in cancer patients who do not engage in causal attributions. Bearison, Sadow, Granowetter and Winkel (1993), found that both paediatric cancer patients and their parents or caretakers who made external types of attributions coped significantly better than those who made internal kinds of attributions or accepted the physician's advice that the cause of illness was unknown (no attribution).

The meaning of cancer to the child revolves around issues of separation-loss and control competence. Van Dongen-Melman and Sanders-Woudstra (1986), cite several studies which attest to these themes: they cite Freud (1952), Shrand (1965), and Geist (1979) who suggested that not only does separation from important people induce loss but also illness itself, these include: loss of health, a loss of body parts through surgery and a loss

of contributing to family life. All developmental milestones are generally in quest of greater autonomy and control. Illness alters this pattern drastically and has a negative impact on the child's sense of control and competence. It deprives the child of control of their daily routine, privacy and relationships with significant people in their lives and results in a dependency on others, restrictions in mobility and activity, subjects the child to continuous medical surveillance and attention, and invasive treatments.

The meanings which families attribute to the cancer experience depend on several factors: the family's experience with cancer and losses; knowledge about the disease; relationships and attachments within the family; and, the degree of cohesion in the family. Seaburn, Lorenz and Kaplan (1992), examined the process implemented by families to develop meanings to chronic illness. They concluded that four basic ideas help to shape and support the family's experience. The first is that families must give their illness experience meaning. The second is that family meanings are passed from one generation to another and are continually evolving. These historical meanings serve to guide families as they contain spiritual, cultural or political elements. The third is that story-telling is a vehicle through which families pass on illness meanings as they provide a structure for current experiences. The fourth is that meanings resulting from stories provide influences and guides for daily living. Die-Trill (2000), suggests that familial beliefs about the cause and prognosis of cancer and the efficacy of its treatments may either aid the patient in achieving optimal psychological recovery or may interfere with his/her adjustment. Bearison et al. (1993) found that parents of children with cancer coped significantly better when they matched their ill child in their causal attributions. Similarity in beliefs facilitates family cohesion, which promotes the adjustment process to the illness.

People's understanding about health and illness is not static and changes depending on their personal circumstances. Lay theories about illness are based on beliefs about the structure and function of the body and ways in which it can malfunction. Although these hypotheses may not always be based on scientifically sound premises, they often give meaning to the person which helps them make sense of what happened and why. Langton

(2000) proposes that lay theories attribute the cause of ill health to one of four possibilities:

- *Within the individual:* the individual is responsible for his/her illness which arise as a result of increased personal vulnerability; eg., changes in diet, lifestyle or behaviour and hence should feel guilty about causing it.
- *In the natural world:* factors such as climate, environmental conditions, infections and accidents are thought to be responsible for the illness.
- *In the social world:* illness is thought to be caused by another person either through magical means (witchcraft, sorcery, the evil eye) or through poisoning or wounds.
- *In the supernatural world:* illness may be seen as punishment from God for sinful behaviour and health may be seen as being restored through penitence and prayer. Where spirits are thought to be the cause they may need to be driven out.

“Culture... is not an optional factor that only sometimes influences health and illness; it is a prerequisite for all meaningful human experiences, including being ill... among all people, not just members of ‘exotic’ cultures” (Burkett, 1991). Cultural diversity results in a wide variation of life-style, health behaviour, religion and language and may affect how people perceive health problems and ill health (Hussein-Rasool, 1995). It is important to recognise that every patient and family has a culture not just people who belong to African ethnic groups or other minority groups. Gotay (1996), asserts that these cultural factors are key variables along with life experiences, socioeconomic status and personality differences, that affect the meaning of cancer for individuals and families, as well as how they cope with the disease.

Theories about the cause of disease differ across cultures and are linked to general cultural explanations for health and illness. The dominant discourse that has prevailed especially in the literature base has been the rational scientific model which asserts that disease results from a specific cause which can be identified and explained through scientific theories and addressed through scientifically based technologies and treatments.

Consistent with this attitude of autonomy and independence, people who subscribe to this predominantly Western perspective, tend to prefer coping styles characterised by active problem solving that are individualised and private, with an emphasis on professional care. While this medical model has generated much research and great strides in the field of cancer, it fails to adequately explain the differences in: preferred styles of coping; decision making; child rearing practices; communication patterns; expression of pain; and, issues pertaining to death and dying, among people from different cultural groups.

Gochman (1992), cited the following studies which illustrates this variability from one culture to the next: Craig and Albino (1982), concluded that isiZulu mothers based their definition of their children's health on eating and playing behaviours, hence a sick baby was one who did not eat or play; in contrast Mc Whirter and Kirk (1986), reported that Australian parents with children diagnosed with acute lymphoblastic leukaemia believed that it was either environmentally determined or a previous infection caused it. Namboze (in Die-Trill, 2000), reported that beliefs about cancer causation in Uganda fell under the following categories: magical, supernatural, infectious and hereditary.

Some Asian cultures place greater emphasis on the interaction between the mind, body, and the environment, thus illness is defined as disharmony existing between these elements. Marsella and Higginbotam (cited in Gotay, 2000), found that treatment was aimed at the restoration of balance through therapies which affect the mind and body as a whole (eg. meditation, acupuncture, herbs combined with prayer, Indian Ayurvedic medicine, and yoga). Buddhism attributes cancer to bad karma: punishment for transgressions in a previous life. Eisenbruch and Handelman (1990), using the case study method, found that a Cambodian family (of Buddhist faith) who had immigrated to Australia, attributed their son's astrocytoma to both their own and his bad karma, and made use of both traditional and western medical interventions. Theories of cancer causation are integrally linked to coping strategies. Gotay (2000), suggests that families who believe that the cancer occurred because of something they or the patient did (eg. many Anglo families in which a smoker was diagnosed with lung cancer) will in all likelihood experience different degrees of stress and enact different coping strategies

compared to a family who believe that the cancer arose from failures in a previous life.

Communication patterns also vary from one culture to the next, therefore the information on diagnosis and prognosis will follow either the open (full disclosure) or protective approaches. Mitchell (1998) points out that a number of elements of disclosure may vary cross culturally, including what is disclosed (ie. diagnosis of cancer vs. a terminal prognosis) the accuracy and level of detail of information and with whom details are shared. His review demonstrates that there are widely differing patterns of disclosure of information about cancer between countries as well as cultural differences within USA. This review distinguished between 'disclosure-dominant cultures' including Australia and Northern Europe in which most practitioners and patients valued open communication about a cancer diagnosis and 'non-disclosure-dominant cultures', in which disclosure was not the rule such as Japan and a number of Southern and Eastern European countries. Physicians in such cultures were of the opinion that non-disclosure upheld the Hippocratic principles of non-maleficence (by not depressing the patient) and beneficence (by maintaining hope). From a cultural perspective the study found that cultural expectations, such as the right of the family to protect the patient are prevalent in many Asian and Hispanic cultures, implying that the family member, not the patient, should be informed. Socio-demographic characteristics also affected disclosure, eg., older and less educated patients were less likely to be informed of their diagnosis.

Some cultural variation also exists regarding family involvement in cancer care. Ali, Khalil and Yousef (1993), compared American and Egyptian families in a study. They reported that Egyptian families have a social obligation to provide hospital care, including food and hygiene, as well as emotional and spiritual support, thus, they concluded that 'cancer is a chronic disease that causes greater disruption to the family than to the patient'. In contrast, they found that in America, the hospital system limits the time and hours that a patient spends with others and prohibits visitors from bringing food for inpatients. People in some cultures may also have great faith in alternative treatments, which may sometimes lead to contradictory advice between Western medical staff and

alternative healing practitioners.

Gotay (2000) cautions that families within a culture are as variable as families between cultures and family individuality must not be overlooked in an attempt to understand cultural patterns. She asserts that personality traits, economic factors (including education, occupation and income), individual and family experiences, past interactions with the health care system and subgroup membership within the larger culture are among factors which may affect a family's reaction to cancer.

4.6. CONCLUSION

There is a considerable body of literature on the psychological and social aspects of childhood cancer. Although the studies presented have been based on sound theoretical assumptions (as outlined in chapter 3), they are classified as being mainly descriptive and anecdotal and have been criticised for their lack of scientific rigor. Nevertheless, these studies have contributed immensely to providing a detailed picture of the 'cancer experience' from the perspective of both the child infected by cancer and their families who are affected by the illness. The above review strongly suggests that cancer poses a myriad challenges for patients and their families and that both patient and family factors play significant roles as determinants of successful adaptation. These findings convey both the weight of the stresses imposed by childhood cancer and the strength and resiliency that these children and their families demonstrate.

There has been much debate in the literature about the severity of the psychosocial consequences of cancer on children. Some studies claim that the effects are minimal (Vance & Eiser, 2001), while others point to psychopathology and social adjustment difficulties (Bessel, 2001; Kashani & Hakami, 1982; Koch et al., 1996). Another body of research has found that both children with cancer and their siblings, evidence the complete range of emotional, social, and behavioural concerns as other children (Noll et al., 1999; and Van Dolgen-Melman & Saunders-Woudstra, 1986). These differences could be attributed to methodological issues, as well as other moderating factors such as: open communication; family, peer and community support; making meaning of the

cancer experience; and, consistency in parenting. The ill child can also have a negative impact on family functioning as it can present the family with additional tasks, responsibilities and worries that may alter the homeostatic balance of the family.

Chesler and Barbarin (1987), aptly summarise the impact of cancer on the family. They propose that the stresses of childhood cancer are exemplified in 3 key family coping tasks: (1) managing internal emotional relationships (eg., the emotional tone of the family changes as fear, pain and hope take on new importance and meaning); (2) adapting to many new practical demands (eg. caring for an ill child, changes in roles and responsibilities, meeting new financial demands); and, (3) maintaining external relationships (eg. having the emotional and physical resources to maintain relationships with extended family and friends, facing the stigma related to the disease, etc). Although psychopathology is not a standard outcome for parents, the cancer experience does have a definitive and far reaching impact on various aspects of their lives. Social networks do not necessarily have a buffering effect. Research suggests that while some families perceive social networks as supportive and providing needed respite, they can also be unsupportive and intrusive, thereby heightening social isolation.

CHAPTER 5

RESEARCH DESIGN AND METHODOLOGY

5.1 RATIONALE

Much of the research in this field was fashioned on the 'deficit perspective', which has focused on how families of chronically ill children differed from other families that were labelled as 'normal', 'control' or 'unaffected'. When the 'with illness' group was compared to the 'without illness' group, the expectation/hypothesis usually was that the former would be characterised as more problematic with poorer problem solving and coping skills. Hence, research into childhood cancer has been conducted primarily within the discourse of psychopathology. Children tend to be characterised within this model as victims of psychologically and physically malign processes, i.e., prone to problems such as separation anxiety, social withdrawal, post traumatic stress disorders, school phobias, isolation and dependency (Dixon-Woods, Young, & Heney, 2002). Simultaneously, the literature has tended to characterise the parents' adaptation to the illness as 'maladjustment'. This model fails to illuminate the processes, which mediate parents' successful adaptation or how parents survive and endure the difficulties associated with childhood cancer.

The literature base on 'childhood illness has traditionally sought parents' reports as proxies for their children. Despite evidence that children are capable of producing rational and coherent accounts, children's views have, until recently, rarely been sought directly by researchers (Dixon-Woods, et al., 2002). Understanding families and health can be facilitated through the identification of important dimensions of the experience of illness. Prime among these dimensions is the notion that children are active participants in the social construction of both their experiences and illness. In this study, children will be the primary respondents. Although the prominence of the family for children is widely

accepted, much remains to be understood of the reciprocal interaction between the child and family. Kazak (1992) argues that it would be more beneficial to understand what differentiates families with children diagnosed with cancer from others, rather than emphasising how they may differ from unaffected families.

From the analysis of the literature review presented in chapter 4, it is apparent that the majority of research contributions in the field of paediatric psycho-oncology originate in America and Europe. In comparison to those countries, South Africa is characterised by differences in population characteristics (greater cultural diversity); third world facilities, resources and economy; recovery from the injustices of an apartheid system; and, disparities in health care services and delivery. There is a paucity of research on the psycho-social experiences and coping mechanisms of children (and their parents) diagnosed with cancer within the South African context. Any effort to study the impact of and adaptation to illness necessitates acknowledgement of the cultural and social diversity of the population under investigation. Ethnic and racial variability in families need to be considered as an integral part of the illness and coping experience, rather than a 'control' variable. The focus of this research is an attempt at understanding how the uncertainty of a childhood illness (such as cancer) with a fluctuating course relates to particular coping strategies exhibited by the child and family.

5.2. RESEARCH DESIGN

This was an empirical study, which used primary data to investigate the research questions. The survey method, utilising a single/one group design was used to gather data. The independent variable (IV) was the diagnosis of childhood cancer and the dependent variables (DV) were the measures of communication, psychological adjustment and coping mechanisms.

Surviving childhood cancer represents a rather unique experiential event, which defies comparison to usual control groups in behavioural research (Koocher, O'Malley, Gogan & Foster, 1980). Kazak (1994) elaborated that relevant questions about the impact of an

illness such as cancer cannot be asked of healthy cohorts because they have not had equivalent experiences. These researchers make a good case for the exclusion of a control group. However, the primary motivation in this instance for excluding a source of comparison is that the aim of this study is the collection of baseline descriptive data relevant to the South African context. Accordingly, a suitable comparative group was unavailable.

5.3. THE RESEARCH METHOD

5.3.1 Research Questions

The study focused on the psychosocial impact and adjustment of children and their families to paediatric cancer. The main question examined 'how the family's responses to illness with reference to communication, psychological adjustment, problem-solving and coping were understood'. The sub-questions which operationalised the main question were as follows:

- What communication style do parents adopt once a child is diagnosed with cancer?
- Do demographic variables such as ethnicity/race and socio-economic status influence the quality of the communication?
- What are the information needs of children diagnosed with cancer and how are they satisfied?
- What is the intensity of the emotional reactions of the sick child and their parents?
- What specific coping strategies do children suffering from cancer employ to cope with the stressful aspects of illness and treatment?
- How do parents cope with the multitude of stressors and problems resulting from their child's illness?

5.3.2 Subjects

Table 5.1: Medical centres where sample was drawn from

Hospital	Percentage %
Johannesburg General Hospital	70%
Chris Hani Baragwanath Hospital	30%
Total	100

Table 5.1 reflects the percentages of participants were recruited from the Johannesburg General Hospital (70%) and the Chris Hani Baragwanath Hospital (30%), which are two paediatric haematology and oncology units in Gauteng. Both centres provide multidisciplinary services to children diagnosed with cancer. The study group comprised 100 children diagnosed with cancer and one or both parents (or an alternative primary caregiver). To avoid distressing parents or introducing bias by interviewing them when their child was in a critical condition, parents were interviewed at least 3 months after the child was diagnosed with cancer. Symptoms differ depending on the type of cancer, illness stage and other child related characteristics (such as developmental status), thus, children of varying ages with different cancer diagnoses and at different stages of their cancer trajectories were sampled to capture core experiences that cut across participant variation. Inclusion criteria for this study were chronological ages 5 to 16 years with a diagnosis of cancer. In order to account for differences in developmental levels participants were divided into three groups consisting of children aged 5 to 7years, 8 to 12 years and 13 to 16 years.

5.3.3 Procedure

After receiving permission to conduct the study from university based ethical review committees (University of Natal, and University of the Witwatersrand), and the participating Children's Haematology and Oncology Units, the study commenced during August 2002. Data collection took place between August 2002 and December 2003. Identification of potential participants was made through the examination of clinic

appointment schedules and discussions with doctors, nurses and reception staff. All potential participants (both children and their parents) were approached personally during their clinic/hospital visits to explain the purpose of the study and gain consent for data collection.

Children and their parents were interviewed at different stages of their illness; namely: less than 6 months; between 6 months and a year; 1 and 2 years; 2 and 3 years; and, 3 and 5 years following the diagnosis. The rate of participation was high with only two families refusing to participate. The reason cited by both families was the lack of time. Ten children were excluded from the study as they arrived at the clinics with siblings and other caregivers, who could neither give consent nor participate in the parent section of the study. Informed consent was obtained from both children and their parents prior to data collection. Data was collected through structured interviews and standardised self-report measures with children and their parents. Prior to the research being operationalised the researcher was concerned about the language issue and whether the structured questions would be easily understood by the respondents. These aspects did not constitute a major problem as only 2% of the sample had difficulty with the language, which was overcome in any event with the aid of an interpreter (a student pursuing a Masters degree in Clinical Psychology).

5.4. INSTRUMENTS

Several measures were used to operationalise the different constructs of the study. The interview method (as discussed on pp 87-89) was the primary method of data collection. A clinical biographical data section provided demographic details about children and their families. This was followed by a structured interview, which was used to measure the variable of communication about the disease. It was necessary to use a structured interview to measure communication, as there is no instrument available for measuring this variable.

Several structured self-report measures (as discussed on pp 89-95) were also used to

measure the challenges posed by the cancer experience and the coping skills and mechanisms used to adapt. One of the advantages to using self-report measures is that it is less time consuming. However, the researcher chose to personally administer these measures to each respondent to ensure that they understood the language and expression used in the questionnaires and to ensure standardisation. The interpretation by people of the events and feelings in their lives are essential sources of information. Thus the interview method accorded the researcher the opportunity to study a number of relevant aspects and relationships of these concepts. An added advantage of using the interview method was the flexibility of attuning the questions to the varying levels of understanding of the respondents. The interview method proved to be beneficial to both the researcher and the participants. From the researcher's perspective it provided rich and fruitful information, while several parents reported that their participation in the study allowed them to express pent up feelings and also reconceptualise their strengths. In total the data collection procedure required approximately one and a half hours per participant and was conducted personally by the researcher.

5.4.1 CLINICAL BIOGRAPHICAL DATA

Demographic details of children and parents were collected to highlight personal characteristics of each family in the study. Children's biographical data consisted of gender, age, educational level, birth rank and the nature of the diagnosis, the duration of the illness and the name of the oncology unit at which treatment was being received. Family details included the age of parents and well siblings, highest level of education, socio-economic status of parents assessed subjectively on the basis of their standard of living, religious and racial affiliation and the type of family system (two parent, single parent or extended family).

5.4.2 COMMUNICATION ABOUT THE DISEASE

A structured format interview was chosen to assess the variable of communication about the disease. Responses were accurately recorded on paper, thus tape recording was not

used to record any information. Questions which comprised the interview were based on key themes identified from the literature and from the researcher's experience as a clinical psychologist involved in psycho-diagnostic assessments and psychotherapy with families affected by cancer. The advantages of standardising questions as well as the manner in which the interview is conducted are: firstly, that it serves the purpose of receiving the same information from all the respondents; and, secondly, it makes an objective quantitative processing of data possible.

For children the interview consisted of:

- *Knowledge of the disease.* This section comprised four questions, which assessed the child's perspective on the nature and seriousness of the disease.
- *Sources of information about the disease.* This section comprised five questions which enquired: who disclosed the diagnosis to the child; the type information the child received about the disease; at what point in time was the information disclosed; and, the initiatives which the child took to gain information.
- *Communication about the disease with parents.* This section comprised three questions pertaining to: which parent is the child's main communication partner: the source of current information; and, the frequency with which the topic is discussed.
- *Communication about the disease with others.* This section tabulates the people within the family with whom the child discusses his/her illness and from whom he/she receives support.
- *Positive and negative experiences about the disease.* These questions assess how the child has appraised the illness experience and what s/he perceives as positive and negative.

The topics included in the interview with parents were:

- *Communication about the disease with the child.* This section contains detailed information which parents have given to the child upon diagnosis, issues

pertaining to prognosis; the nature of the information withheld from the sick child; the frequency with which the illness is discussed; information which parents have withheld from the child; and, who takes the initiative to discuss illness related concerns. Parents were also asked about their feelings in general and whether they expressed their own sorrow and grief in the presence of the sick child and whether the parent enquires about their child's concerns and grief. The last question addressed the issue of death among fellow patients and the nature of parental communication with reference to this issue.

- *Communication about the disease with siblings.* This section consisted of three questions relating to the type of information, which parents have given to siblings about the sick child and the nature of questions asked by siblings.
- *Communication about the disease with their partner.* This section assesses the type of support, which the partner offers, who initiates the discussion and the frequency of communication.
- *Support needs.* This section enquires about the support needs of parents pertaining to: informational needs; support from multi-disciplinary staff; other parents; religious/ spiritual support; and, whether parents participate in a support group.
- *The child's behavioural difficulties.* The parent was asked about the range of behavioural difficulties experienced by the child, these included: sleeping problems, eating problems, bed wetting, pain, playing sport; problems faced at school and with socialisation.

5.4.3 ASSESSMENT OF PSYCHOLOGICAL IMPACT

CHILDREN'S DEPRESSION RATING SCALE, REVISED (CDRS-R; Poznanski and Mokros, 1995)

The CDRS-R is a brief rating scale modelled after the Hamilton Rating Scale for Depression. It is a validated 17-item, clinician-administered instrument for the assessment of depressive symptoms in children aged 6 through to adolescence. The interviewer rates 17 symptom areas including: impaired school work; difficulty

having fun; social withdrawal; appetite disturbance; sleep disturbance; excessive fatigue; physical complaints; irritability; excessive guilt; low self esteem; depressed feelings; morbid ideation; suicidal ideation; excessive weeping; depressed facial affect; listless speech; and, hypo-activity. Most of these symptom areas are rated on a 7-point-scale, thereby allowing the interviewer to capture slight but notable changes in the child's symptoms. The CDRS-R gives a single Summary Score, which is converted into a T score (mean = 50, SD = 10) and an approximate percentile using a scoring thermometer. Each T score has a corresponding interpretative statement. Scores are primarily used to rate the severity of depressive symptomatology and not to diagnose depressive disorders. For the purposes of this study, normative data (t scores) rather than raw scores were used. Each symptom can also be interpreted to provide a description of how children coped with various aspects of their lives following their cancer diagnosis.

SPENCE CHILDREN'S ANXIETY SCALE (SCAS; Spence, 1997)

The SCAS is a child self-report measure designed to evaluate symptoms relating to separation anxiety, social phobia, obsessive-compulsive disorder, panic-agoraphobia, generalised anxiety and fears of physical injury. The measure consists of 44 items, of which, 38 reflect specific symptoms of anxiety and 6 relate to positive filler items to reduce negative response bias. Items are randomly allocated within the questionnaire. Children were asked to rate on a four-point scale ('never', 'sometimes', 'often' or 'always') the frequency with which they experience each symptom. The responses are scored: 'never' = 0; 'sometimes' = 1; 'often' = 2; and 'always' = 3. The subscales were computed by adding the individual item scores. The 0 to 3 ratings on the SCAS are summed up for the 38 anxiety items to provide a total score (maximum = 114) with high scores reflecting greater anxiety.

The psychometric properties of the scale were published by Spence (1998). In the standardisation study, the SCAS was found to have high internal reliability with a coefficient alpha of 0,92 and a Guttman split-half reliability of 0,90. The test-retest

reliability in a sample of 120 children retested after 6 months was found to be 0,51 for the total score. The concurrent validity of the SCAS was examined with a sample of 311 children. The mean total score was 30,56 (S.D. = 16,75). The SCAS correlated strongly with the Revised Children's Manifest Anxiety Scale ($r = 0,73, p < 0,001, N = 311$) and significantly, but less strongly, with mothers' ratings of internalising problems ($r = 0,34, p < 0,01, N = 101$), but not externalising problems, on the Child Behaviour Checklist.

THE GENERAL HEALTH QUESTIONNAIRE (GHQ; Goldberg, 1972)

The GHQ is a self-administered screening instrument used to detect psychological morbidity. Several versions of varying length are available, but for the purposes of this study the 28-item version was used. According to Goldberg (1972) the GHQ was designed to identify two main classes of problems: "inability to carry out one's normal 'healthy' functions and the appearance of new phenomena of a distressing nature". This questionnaire was chosen because it is widely used to measure non-psychotic psychological impairment in adults living in the community and considerable information is available about its validity and reliability (Goldberg, 1978). In addition to the total score, the GHQ-28 provides scores on four subscales, measuring somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. Items are scored using a Likert-type scale (0-1-2-3) for response categories. The total score on the questionnaire ranges from 0 to 84, while scores on subscales range from 0 to 21. Scores are interpreted as indicating the severity of psychological disturbance along a continuum. The reliability of the GHQ is indicated by the test-retest coefficient of 0,90. The scale has been tested in many countries and showed remarkably consistent validity results. The validity of the GHQ-28 was 0,76 when correlated with the Clinical Interview Schedule. A correlation of 0,73 was obtained with the clinical depression rating and of 0,67 with the anxiety rating. The sensitivity for the GHQ-28 was 85,6% at a specificity of 86,8%.

5.4.4 ASSESSMENT OF ADJUSTMENT AND COPING DIMENSIONS

KIDCOPE

To date, the only assessment tool specifically designed to investigate distress and coping in paediatric patients is the KIDCOPE checklist. This instrument was developed by Spirito, Stark and Williams (1988) to provide a brief measure to identify coping in children and adolescents. The construction of this measure was based on Lazarus and Folkman's (1984) definition of coping and assesses frequency and type of coping strategies used by children. Kidcope is a checklist designed to assess 10 specific cognitive and behavioural coping strategies: distraction, social withdrawal, wishful thinking, self-criticism, blaming others, problem-solving, emotional regulation, cognitive restructuring, resignation and social support. The scale is available in two versions: one for younger children aged 7-12 years and one for adolescents aged 13-18 years. The adolescent version of the scale consists of 10 items, while the version for younger children consists of 15 items that are collapsed to the same 10 scoring categories as the older version.

The checklist is made up of four main parts: the stressor within the setting, the distress felt by the child in relation to the stressor, the child's way of coping with the stressor and the helpfulness of that coping strategy. The subjects were instructed to identify specific stressors related to their cancer experience, to rate their level of distress in relation to the stressor and rate the frequency (Frequency Scale) with which they used a particular coping strategy to deal with cancer related problems. For the adolescent version, the Frequency Scale is completed by using a 4-point Likert-type scale ranging from "not at all" to "almost all the time". For the younger child version, it is answered "yes" or "no." In order to make the older and younger versions comparable, each of the items on the Frequency Scale was coded as either occurring, "yes" (ie. the coping strategy was used 'sometimes,' 'a lot of the time,' 'almost all of the time') or not occurring, "no" ('not at all'). Moderate test-retest correlation coefficients have been reported for the Kidcope, but the concurrent validity has been demonstrated by moderate to high correlations of

Kidcope items with other commonly used coping scales (Spirito, et al., 1988).

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES (FCOPES)

The FCOPES were developed by McCubbin, Olson and Larsen (1981) to identify the problem-solving attitudes and behavioural strategies employed by families in difficult or problematic situations. The theoretical base for the FCOPES was drawn from a sociological research tradition based on family stress literature. The Double ABCX Model has been explained in detail in chapter 3. This measure attempts to integrate two levels of functioning: internal family coping strategies, ie., the intra-familial processes that use resources found within the family system; and, external family coping strategies, ie., how the family interacts with the social environment to acquire resources from outside the immediate family system. The measure is founded on the hypothesis that families who display more coping strategies of both types will adapt more successfully to stressful events or situations and therefore experience heightened well-being.

Respondents are asked to rate how well the 30 statements about coping behaviour describe their own family's responses to problems. The degree to which the respondent agrees or disagrees with a statement is scored on a Likert Scale from 1 'strongly disagree' to 5 'strongly agree'. The FCOPES comprises five subscales:

1. *Reframing/redefining* events to make them more manageable (items 3, 7, 11, 13, 15, 19, 22, 24).
2. *Passive appraisal*, a reference to the ability to accept problematic issues (items 12, 17, 26, 28).
3. *Acquiring social support* from relatives, friends, extended family and neighbours (items 1, 2, 5, 8, 10, 16, 20, 25, 29).
4. *Seeking spiritual support* (items 14, 23, 27, 30).
5. *Mobilising the family to acquire and accept help* from community resources (items 4, 6, 9, 21).

Summary scores are obtained for each subscale and the total scale by adding the appropriate items. Items 12, 17, 26 and 28 are reverse scored. The total scale scores

provide information on how many coping strategies are used by the family, while the subscale scores for each coping strategy creates a profile demonstrating the extent to which each one is utilised. The FCOPES has been studied with several thousand respondents although specific demographic information was not reported. Norms were as follows: total score – mean = 93, 3 (SD = 13,62); acquiring social support – mean = 27,2 (SD = 6,4); reframing – mean = 30,2 (SD = 4,8); seeking spiritual support – mean = 16,1 (SD = 3,05); mobilising of family – mean = 11,96 (SD = 3,4); and, passive appraisal – mean = 8,55 (SD = 3,01). The reliability has very good internal consistency with Cronbach's alpha of 0,86. The alpha reliability of the five individual subscales ranged from 0,62 (Passive Appraisal) to 0,84 (Acquiring Social Support). Test-retest reliability for the total scale was 0,81, while test-retest reliability for five factors over a four-week interval ranged from 0,61 to 0,95. Construct validity was assessed through factor analysis, with 8 initial factors collapsed into 5, each having an eigenvalue greater than 1,0. The FCOPES also has good concurrent validity, correlating with several other family measures.

COPING HEALTH INVENTORY FOR PARENTS (CHIP)

The CHIP was developed by Hamilton, McCubbin, McCubbin, Nevin, and Cauble in 1983 to measure parental coping styles (McCubbin, 1991b). As with the FCOPES the theoretical base for the CHIP was based on the Double ABCX Model. This instrument aims to assess parents' response to the management of family life when they have a child who is chronically ill. It contains 45 items, which is descriptive of coping behaviours. The CHIP has three subscales developed through factor analysis:

1. Coping pattern I – Maintaining family integration, cooperation and an optimistic definition of the situation (items 1 to 19).
2. Coping pattern II – Maintaining social support, self-esteem, and psychological stability (items 20 to 37).
3. Coping pattern III – Understanding the medical situation through communication with other parents and consultation with medical staff (items 38 to 45).

The CHIP is a self administered instrument which is scored on a four-point Likert scale (0 = not helpful; 1 = minimally helpful; 2 = moderately helpful; and, 3 = extremely helpful. Scores for each subscale are derived from the sum total of each subscale. The normative data for this measure was based on results of 308 parents who had a chronically ill child. Mean scores on Factor I were 40 (SD =15) for mothers and 36 (SD =20) for fathers; on Factor II – 28 (SD = 12) for mothers and 25 (SD = 15) for fathers; and on Factor III – 15 (SD =7) for mothers and 12 (SD = 8) for fathers. Chronbach alphas computed for the items on each coping pattern, indicated respectable reliabilities of 0,79, 0,79, and 0,71 respectively. The CHIP has fair concurrent validity with several correlations with the Family Environment Scales. The CHIP also has good known-group validity, significantly differentiating between high and low conflict groups.

5.5. DATA ANALYSIS

The interview material was subjected to both qualitative and quantitative analysis. Data was prepared for quantitative analysis using a coding process within a reductionist framework. Responses to each open-ended question were examined and major themes were identified. Using this method was advantageous as it generated categories based on the current research as opposed to placing data in predetermined categories. Individual responses were then placed into categories and assigned numerical codes and entered into the SPSS programme (version 11,0) for analysis. In the case of the items on the structured questionnaires, the pre-coded categories based on the question/answer format were used.

Data analysis involved descriptive statistics and inferential statistics. All the statistical operations were carried out using the SPSS programme. The communication variables were analysed by calculating percentages, means and standard deviations. Contingency tables were used to plot associations between different variables. The standardised tests were analysed according to manual norms, in addition an item analysis was conducted on variables/scales which showed elevations. Inferential statistic was also performed to test relationships between sociodemographic variables and adjustment and coping variables.

The design of the study was such that all the data was obtained at one point in time hence the analyses are at best associational/correlational. Thus, this research cannot with any certainty make statements about causality.

CHAPTER 6

RESULTS AND DISCUSSION

While psychosocial oncology is an important research track at the University of Kwa-Zulu Natal, much of the focus thus far has concentrated predominantly on adults. Hence, while paediatric psychosocial oncology is now well established in Europe and in America, similar initiatives are, however, rare in Africa. On the African continent, psychosocial services are scarce and often a luxury although the importance of psychosocial variables as mediators in the paediatric cancer outcomes have been widely recognised. Thus, in order to provide a more holistic service it becomes imperative to assess the psychosocial needs and resources of both children and parents who endure the illness, which regrettably, would be beyond the scope of a single study. Hence, this research is limited to collecting baseline information on how parents and children communicate about the illness, their emotional responses and the psychological resources that they utilise to deal with the experience. Given the nature of the study no specific hypotheses were formulated or tested. The most significant results which emerge are summarised below:

1. *What are the information needs of children and their families and how are they satisfied?*
 - The medical team was the primary provider of information to children, their parents and their siblings.
 - Although both children and their parents were curious about aetiology and the prognosis of cancer they settled for the standard information provided by the cancer unit and did not see the need to seek out additional sources.
 - Other parents whose children were diagnosed for longer periods of time were an important source of information and advice.

- Children also relied on fellow patients to provide them with information on a range of issues.
- Siblings needed to understand the cancer trajectory and thus asked more questions, which were answered more often by the medical staff than their parents.

2. *What communication style do parents adopt once the child is diagnosed with cancer?*

- Parents adopted a protective style and as such communication was difficult, closed and limited to factual information of and concerning the disease.
- Most parents did not engage with their children at an emotional level and as a result children blocked out their feelings and did not discuss emotional pain.
- Parents also did not initiate discussions around the illness but instead waited for questions before giving information. Questions pertaining to death and prognosis were not answered directly but children were rather encouraged to be optimistic.
- Overall Black parents tended to give their children less information in contrast to White parents.

3. *Do demographic variables such as age of child, socioeconomic status and race influence the quality of communication?*

- The age of the child was an important factor with reference to the amount and complexity of information given to children: adolescents were given more information about the treatment and prognosis; while younger children were given a limited amount of information pertaining to treatment procedures.
- White parents tended to communicate more openly with their children in comparison to Black parents.

4. *What is the intensity of the emotional reactions of the sick child and their parents during the treatment phase?*

- Children did not experience clinical depression or anxiety however they manifested specific symptoms which implied adjustment difficulties.
- Parents did not experience psychopathology *per se* but did manifest symptoms of anxiety and depression. Black parents experienced somatic symptoms which appeared to mask their depression.

5. *What specific coping strategies do children suffering from cancer employ to cope with the stressful aspects of illness and treatment?*

- Most children used problem focused behaviours to cope with their illness. Younger children used blaming more often, while older children and adolescents used cognitive restructuring, problem solving and social support.

6. *How do parents cope with the multitude of stressors and problems resulting from their child's illness?*

- Parents coped by actively seeking out support from friends and the extended family.
- They made meaning of this experience and reframed it to suit their needs for psychological stability and in this way managed to maintain a level of optimism.

6.1 DEMOGRAPHIC AND BACKGROUND FACTORS

Table 6.1 presents a summary of the background characteristics of 100 children who comprised the final sample of this study. Of the 100 children and their families who were recruited, 52% were female and 48% were male. Children ranged in age from 5 to 16 years, with a mean age of 10,08 years ($SD = 2,699$). In total 17% of the children in the sample were between 5 and 7 years, 63% were between 8 and 12 years, while 20% of the sample consisted of adolescents between the ages of 13 and 16 years. The most frequent

diagnosis was leukaemia (37%). Leukaemia is also the most common childhood cancer both worldwide and in South Africa. Further diagnoses were: Ewing's sarcoma (2%), medulloblastoma (6%), neuroblastoma (8%), nephroblastoma (12%), Burkitt's lymphoma (3%), Hodgkin's disease (8%), osteosarcoma (4%), lymphosarcoma (6%), rhabdomyosarcoma (5%), fibrosarcoma (4%) and retinoblastoma (5%).

Table 6.1 Demographic characteristics of the children diagnosed with cancer

Characteristic	n =100	Percentage %
<i>Age of children</i>	<i>mean = 10,08 years</i>	<i>SD = 2,699</i>
5 to 7 years	17	17
8 to 12 years	63	63
13 to 16 years	20	20
<i>Gender</i>		
Male	48	48
Female	52	52
<i>Nature of the diagnosis</i>		
Leukaemia	37	37
Ewing's sarcoma	2	2
Medulloblastoma	6	6
Neuroblastoma	8	8
Nephroblastoma	12	12
Burkitt's lymphoma	3	3
Hodgkin's disease	8	8
Osteosarcoma	4	4
Lymphosarcoma	6	6
Rhabdomyosarcoma	5	5
Fibrosarcoma	4	4
Retinoblastoma	5	5
<i>Length of time since diagnosis</i>		
Under 6 months	20	20
6 months to 1 year	22	22
1 to 2 years	31	31
2 to 3 years	15	15
3 to 5 years	12	12

Children and their parents were interviewed at different stages of their illness: 20% had a diagnosis for 6 months or less; 22% between 6 months and a year; 31% between 1 and 2 years; 15% between 2 and 3 years; and, 12% between 3 and 5 years. The children

Table 6.2 Demographic characteristics of parents

Characteristic		Percentage %		
<i>Educational level</i>		<i>Mother</i>	<i>Father</i>	
Postgraduate		5	5	
University/college		12	18	
Matric		28	35	
High school		28	12	
Primary school		21	16	
No schooling		6	2	
Unreported		12	0	
<i>Composition of the family</i>				
Two parent family			50	
Single parent family			17	
Extended family			33	
<i>Ethnic Group</i>				
African			46	
Indian			11	
Coloured			3	
White			38	
Other			2	
<i>Socioeconomic status of family</i>				
Higher			14	
Middle			42	
Lower			44	
<i>Age in years</i>	<i>minimum</i>	<i>maximum</i>	<i>mean</i>	<i>standard deviation</i>
Mothers	24	61	37,4	6,423
Fathers	25	56	40,54	6,656

interviewed in this study were co-operative, eloquent and candid about their experiences. When children exhibited a tendency to give one word or single phrase answers, gentle prompting and/or a ‘story telling’ technique was used. Generally, they openly shared both their positive and negative experiences and thoughts.

Table 6.2 shows the demographic characteristics of parents in the sample. Parents were aged between 24 years and 61 years. The mean age of mothers in the sample was 37,4 years (SD = 6,423) with a range of 24 to 61 years. For fathers the mean age was 40,54

years (SD = 6,656) with a range of 25 to 56 years. Sixty percent of the sample were Black ('African', 46%; 'Indian', 11%; 'Coloured', 3%) while 38% were White. In terms of family constellation 67% were nuclear families living as either two-parent (50%) or single parent (17%) units, while 33% lived in extended family units. The majority of the sample (44%) fell into the lower income category, 42% were considered to be of middle income status, while the higher income bracket comprised 14%. The socio-economic disparities which exist amongst South Africans along racial lines are reflected in this sample (table 6.3): the majority (67%) of the Black families were of lower income levels in comparison to 5% of the White families; most White families (68%) belonged to the middle income category in contrast to 27% of Black families; whilst 26% of the White families came from the higher income category as opposed to 7% of Black families.

Table 6.3: Socioeconomic status of family based on ethnic affiliation

Ethnic group	Socioeconomic status		
	lower	middle	high
White (n=38)	2 (5%)	26 (68%)	10 (26%)
Black (n=60)	40 (67%)	16 (27%)	4 (7%)
Other (n=2)	2 (100%)		

The educational levels ranged from no formal schooling to postgraduate qualifications. The discriminatory regulations and restricted access to education, which prevailed during the apartheid era, were reflected in the educational levels achieved by parents. Overall, White parents had attained higher levels of education: 32% of fathers and 26% of mothers had a matric and post matric qualifications; only 4% of fathers and 12% of mothers had below a high school qualification; while none of this group were uneducated. Amongst the sample of Black parents: 25% of fathers and 19% of mothers had a matric and post matric qualification; 26% of fathers and 36% of mothers had below a high school level of education; while 7% (2% of mothers and 5% of fathers) had no formal education.

Eighty nine percent of the mothers (or female caregivers) were the primary respondents,

in comparison to 2% of fathers, while 9% of the children were accompanied by both parents. In South Africa, gender disparities still exist in child rearing; the child's well-being is still firmly planted in the domain of the mother, which explains why they were the primary respondents. Thus, if future research requires comparative information alternative arrangements need to be put in place to access fathers. When both partners were present, they were interviewed together. Irrespective of the duration since diagnosis, parents were able to give detailed accounts of the events which took place after their child's diagnosis. Many parents recalled specific dates of procedures, their child's response to treatment and personal conversations with significant people in their lives. These narratives facilitated parents' descriptions of their experiences. In the literature (Reay et al., 1998 and Koch et al., 1999) on the emotional reactions of parents of children with cancer, differences in the emotional reactions between mothers and fathers are regularly reported. These differences could not be adequately explored in this study due to the small sample size of fathers. Instead differences between the different socioeconomic and ethnic groups were assessed.

6.2 COMMUNICATION ABOUT THE DISEASE

Table 6.4: Primary source of information to the child

Information received from	Percentage %
Doctor/oncology team	41
Mother	42
Father	2
Both parents	7
No one	8

The haematology and oncology units, from which the sample was drawn, subscribed to an 'open approach' to communication. Hence, children and their parents are informed by the paediatric oncology team about the disease, its treatment and side effects from the outset. Parents are also advised to adopt an open communication approach with their children. Table 6.4 examined who the child considered to be their primary source of

information; the type of information the child received (table 6.6) and the point in time at which the child was informed (table 6.5). Although the primary source of information to most children was their mothers (42%), followed by the doctors or medical staff (41%), this difference was negligible. Children, who received information from doctors/medical staff, were conversant in the medical terminology and the hospital routines. Eight percent of the children reported not receiving any information while a small percentage (2%) of fathers acted as the primary source of information to children. Although 50% of the sample lived in two-parent nuclear family households, both parents were the primary source of information for only 7% of the sample. Many of the mothers who were the primary source of information revealed that the reason their husbands did not participate in the disclosure were that: 'they were busy at work'; 'were too stressed'; or 'had difficulty with expressing feelings and were afraid of becoming emotional'. One mother reported that her husband was very angry because she (the mother) gave consent for the child's eye to be operated on as he was not convinced that they should follow the medical route and preferred for the child to be treated by traditional healing methods.

Table 6.5: Point in time when children were informed about their illness by the primary source

Point in time	Percentage %
Upon diagnosis or shortly after	61
Much later	31
Not at all	8

Table 6.5 illustrates the point in time at which children were informed about their disease. Most (61%) of the children reported receiving information about their illness upon diagnosis or shortly thereafter, 31% of the children learnt of their illness about 2 to 6 months after their diagnosis, while 8% reported that there was no discussion about their illness, leaving them to formulate and test their own hypotheses pertaining to why they needed hospitalisation and constant surveillance. These findings confirm that most children were informed about their illness during the initial stage, when they came into contact with the oncology department for the first time. Many studies have confirmed that

information pertaining to the disease, the medical terms and treatment are generally given to children during the early stages of the disease, while children were generally informed about relapse/recurrence after the completion of treatment.

Table 6.6: *Types of information children report receiving from the primary source*

Categories of information	Percentage %
Diagnosis only	15
Treatment only	38
Diagnosis and treatment	29
Diagnosis, treatment and prognosis	10
No information	8

The types of information which children reported receiving varied greatly and is reflected in table 6.6. Majority (38%) of the children remembered receiving information pertaining to details about treatment, 29% were informed about both their diagnosis as well as treatment procedures, 15% reported receiving only information about their diagnosis, a smaller percentage (10%) appeared to have received the full range of information, ie.; diagnosis, treatment and prognosis, while 8% claimed to have received no information.

Table 6.7: *Categories of information which parents report giving children of different age groups*

Information about	Age groups		
	5-7 yrs n = 17 %	8-12 yrs n =63 %	13-16yrs n = 20 %
Information on a need to know basis	47	40	25
Diagnosis, treatment, hospitalisation, but not death or seriousness	18	32	40
Diagnosis, treatment, prognosis, death	14	16	30
No information	12	13	5

When explaining treatment, the high chances of cure were emphasised by both parents and oncology staff, while the possibility of death was not discussed as part of the range of possibilities.

Table 6.8 shows a high level of correspondence between the information which parents reported giving their children, with what the children reported receiving. Most (38%) parents were comfortable with informing children on a ‘here and now’ basis. Thirty five percent of the children confirmed that discussions were limited to what they needed to know about procedures/treatments which were occurring on the day in question. Hence, there was little or no mention of the diagnosis or the term ‘cancer’. Most parents found it difficult to use the word ‘cancer’ as it had ‘negative’ and ‘scary’ consequences and thus were afraid of startling their children. Some parents also reported that they avoided using the term because they felt that their children were too young to understand the meaning of the word. A mother whose husband died 2 months after her child was diagnosed, experienced major personal distress at hearing the word and thus could never articulate what caused her husband’s death, even during the interview. She explained that her husband died of the ‘same thing that her child had’. The literature confirms that people who have suffered previous losses from cancer are usually aware of the life threatening nature of the illness and the devastation caused by the cancer trajectory to both the sufferer and their significant others (Bishop, 1994).

Table 6.8: Categories of information which parents reported giving their children, and children reported receiving from their parents

Information about	Information about the disease	
	Parents reported giving children	Children received from parents
Information on a need to know basis	38%	35%
Diagnosis, treatment, hospitalisation, but not death or seriousness	31%	30%
Diagnosis, treatment, prognosis, death	20%	21%
No information	11%	14%

Thirty one percent of the parents chose to give their children some details about their illness including the diagnosis and the reasons for various procedures and hospitalisations. The diagnosis was however not labelled as cancer, but as a 'growth', 'tumour' or 'bad blood'. While parents chose to provide a cross spectrum of information they did not mention the seriousness of the disease, the possibility of the child not recovering or the life threatening nature of cancer. According to these parents, giving children too much information on the possible terminal nature of the illness may result in a negative effect. This was confirmed by 30% of the children. The amount and complexity of information which children received varied with age (table 6.7). Parents were able to discuss treatment, the seriousness of the illness and also the prognosis with adolescents.

Twenty one percent of the parents reported giving their children all the information which they possessed about the disease. Discussions included diagnostic information, the various treatment procedures and side effects, the seriousness of the disease and the possibility of death. These parents believed that open communication facilitated better emotional preparedness and thus resulted in a positive effect. Open communication was confirmed by 20% of the children interviewed. Although 11% of the parents reported not giving their children any information, none of the children interviewed were completely ignorant about their illness, thereby confirming that many of them received information from alternative sources and environmental cues. While 11% of the parents reported not giving any information, 14% of the children reported that they did not receive information from their parents. Whilst 30% of the children chose not to ask family members questions about their illness, all of them claimed that they had sources in their environment that could provide some information. Most children admitted that when they did ask questions of either medical staff or family members they received an honest response.

Table 6.9 lists the information given by parents to children of different age groups. Information which parents gave their children appeared to increase with age. This was confirmed by many parents who spoke about withholding certain information because

they presumed it to be beyond the scope of their children's understanding.

Table 6.9: Categories of information which children in the different age groups reported receiving from their parents

Information about	Age groups		
	5-7 yrs n = 17 %	8-12 yrs n = 63 %	13-16yrs n = 20 %
Information on a need to know basis	53	33	25
Diagnosis, treatment, hospitalisation, but not death or seriousness	12	32	40
Diagnosis, treatment, prognosis, death	24	16	30
No information	12	17	5

The problem of what to tell or not to tell the sick child occurs within an atmosphere of uncertainty. Table 6.11 reflects the information which parents reported withholding from sick children. Most parents (92%) reported that they had not prepared their children emotionally, but instead adopted an over-protective approach in which they buffered the child from negative emotions. However, this was successful as long as the child remained in the protective environment of the home and hospital. Many parents also reported that they experienced difficulty with their own feelings and thus did not have the emotional resources to prepare their children adequately for the emotional consequences of cancer. Parents reported that the uncontrollability and uncertainty with regards to the outcome of treatment resulted in their feelings vacillating between fear and hope. This made it especially difficult as they emphasised optimism to the child but some children reported that they noticed how 'worried' and 'frightened' their parents became when they went through 'bad' patches.

A high percentage of the parents (89%) blocked out the possibility of their child's death, hence it was a topic they were not willing to actively discuss with their children. In addition, they also did not want to frighten their children. The possibility of a relapse/recurrence only became a concern after treatment was completed. Most parents

Table 6.10: Categories of information which parents from the different ethnic groups reported giving their sick child

Information about	White n = 38	Black n = 60	Other n = 2
Information on a need to know basis	9(24%)	29(48%)	0
Diagnosis, treatment, hospitalisation, but not death or seriousness	14(37%)	16(27%)	1(50%)
Diagnosis, treatment, prognosis, death	13(32%)	7(12%)	0
No information	2(5%)	8(13%)	1(50%)

(90%) did not want to 'think that far ahead' because the thought of having to go through the whole process again was sometimes inconceivable; therefore, they chose not to divulge this information to their children. Over half (56%) of the parents reported that the tenor of the information they received from doctors was optimistic, hence there was no need to inform the child about the possibility of death. Black parents appeared to experience more difficulties when communicating about all facets of the illness in comparison to White parents (table 6.10). The reasons which parents gave for this difficulty were: (i) at a cultural level matters of such importance are not generally discussed with children but instead are the domain of the elders of the family (this attitude is similar to the paternalistic protective approach); (ii) some parents indicated that they experienced difficulty comprehending the complexity and seriousness of the disease and did not know how to engage on the matter with their child; (iii) parents also withheld information because they believed it in the best interests of the child; and, (iv) other parents felt the imparting of disease related information was the domain of the medical staff and thus felt that they should not encroach upon their territory.

The information needs of the sick child are reflected in table 6.12. Forty percent of the children declared that they did not need to know much about their illness either because it was unnecessary or the knowledge they possessed was adequate. However, many of the children were very reluctant to continue attending outpatient clinics and frequently

Table 6.11: Information which parents reported withholding from sick children

Categories of information	Percentage %
Information relating to death and dying	56
Information relating to a range of emotions	92
Information about the possibility of relapse/recurrence	90
The possibility of not getting better	89

enquired about the need for the prolonged treatment. The majority of parents chose not to volunteer information spontaneously, but waited for the sick children to initiate the discussion. The category of information which children sought most related to their attempts to understand what caused the illness. Seventy six percent of the children asked questions such as: ‘why did I get sick?’; ‘what did I do that was wrong?’; ‘am I being punished for something?’ and ‘who gave me this disease?’

Table 6.12: Information needs of the sick child

Information needs	Percentage %
No information needs	40
Questions about the causes of the disease	76
Questions about the negative effects of treatment	64
Questions about the possibility of dying	22

Many children (64%) sought answers to questions relating to the treatment and its side effects. Some of these questions emanated from their observations of the pain, discomfort and death which they experienced vicariously through fellow patients. Questions included: ‘will I go bald?’; ‘why do I have to get so sick to get better?’; ‘why can’t I play with others?’; ‘why does the treatment have to go on for so long?’; ‘why do I need to have so many needles?’

A smaller percentage of children (22%) enquired about the possibility of dying, this was confirmed by the report that only 22% of children knew that they would possibly not

recover from their illness and 23% of children were knowledgeable about the possibility that their disease could result in death. According to parents, the questions which they dreaded most were: ‘do I have cancer?’; ‘when will I get better?’; ‘am I going to die?’ Irrespective of the age of the child all of these parents denied the possibility of death and emphasised the hopeful aspects.

Children’s information needs revolved around making sense of this disease, the prognosis and the invasive nature of treatment. Whenever they were able to anticipate the impact of treatment, they also felt more settled and less anxious. Within the family, children (36%) relied more on their mothers than fathers (7%) or siblings (6%) for their information and emotional support needs.

Table 6.13: Categories of knowledge about the disease which children possess irrespective of the source

Information received by the child	Percentage %
<i>Diagnosis</i>	
Seriousness of illness	29
Long duration of illness	46
Tumour/growth/medical term	92
Cancer	74
<i>Treatment</i>	
Day to day procedures	71
Hospitalisation and various procedures	39
<i>Prognosis</i>	
Possibility of not getting better	22
Possibility of dying	23

Table 6.13 reflects children’s specific knowledge of the disease based on interviews. With regards to diagnostic issues, 92% of the children knew that they had a tumour, growth or could label the type of cancer which they had, eg. leukaemia, neuroblastoma or Hodgkin’s disease. Although only 51% of the children reported that their parents used the word cancer when discussing the disease, 74% were aware that they suffered from cancer. Fewer children were aware of the seriousness of their disease (29%), however, over time children come to realise the long term nature of the disease (46%).

The majority of the children (71%) were well informed about day to day procedures. The main source of those kinds of information was the doctors and nurses who explained the procedures in some detail and showed the children the equipment that they would be using. Children, who were in-patients at the time, also discussed these issues with other patients who were a source of encouragement and support. Most of the children who are patients at the Chris Hani Baragwanath hospital relied on each other for psychosocial support, as their parents were not always present, due mainly to socioeconomic difficulties. Older children sometimes took on a ‘big brother/sister’ role. The researcher witnessed an incident where a younger child (6 year old) was afraid to take a blood test and became visibly upset; an older child (10year old) intervened and asked the doctor to demonstrate the procedure on him to help alleviate the younger child’s anxiety. The doctor obliged, the older child then placed the younger child on his lap and assisted the doctor to complete the procedure. Children also tend to rely heavily on fellow patients as a major source of information. A number of children and their parents reported that their children learnt about ‘cancer’ from other children in the ward. The warmth and camaraderie which some of these children share demonstrates the strength of the human spirit and their resilience.

Table 6.14: Frequency of communication about the disease between parents and sick child

Frequency of communication	Communication	
	initiated by child	initiated by parents
Several times a week	19%	17%
Once a week	26%	20%
At least once a month	28%	25%
Less than once a month	29%	36%

Table 6.14 examines how often children and their parents discuss their illness as well as who initiates the discussion. Overall, children and parents reported that they discussed the disease more frequently during the first two to three weeks following diagnosis. Thereafter, the topic only resurfaced shortly before scheduled appointments for

treatments/checkups, or during periods of distress. Children seemed to initiate the discussion more frequently than parents. The content of the communication was usually dominated by treatment related issues: ‘how much longer do I have to go to the hospital’; ‘am I going to get very sick again’; ‘is it going to hurt’. Reasons which parents gave for not initiating the discussion as frequently as their children, related to not wanting to burden the child with their concerns and worries, one parent summarised her sentiments in the phrase: ‘one should let sleeping dogs lie’. Despite these statistics, children indicated that they were satisfied with the frequency and quality of their communication with their parents. Some parents felt unsure about whether the quality and frequency of their communication was adequate.

Table 6.15: Information given to siblings and sick children by parents

Type of information received	Information about disease given to	
	siblings	sick child
Information on a need to know basis	35%	38%
Diagnosis, treatment, hospitalisation, but not death or seriousness	22%	31%
Diagnosis, treatment, prognosis, death	13%	20%
No information	19%	11%
N/A (siblings were too young)	11%	

Parents were asked what information they gave to their well children about the sick child’s illness. Table 6.15 shows the categories of information given to siblings. For the purposes of comparison, the information given to the sick child is also reflected in the table. Overall, siblings received less information than the sick children about the different aspects of the disease: 13% were given information on all aspects of the illness including the possibility of death, most (35%) of the siblings were informed on a need to know basis, although 22% of them were told something about the diagnosis, treatment and hospitalisation, they were not informed by their parents about the possibility of their brother/sister dying. Eleven percent of the sample had either no siblings, or siblings who had not attained verbal proficiency as a function of their age/developmental stage.

Parents found it emotionally distressing and very difficult to communicate with siblings about aspects of diagnosis and prognosis and simultaneously deal with their questions and queries. Most parents reported that they felt relieved that the medical staff discussed their sick child's diagnosis with their well children. Eighty eight percent of the parents confirmed that a member of the oncology team informed their well children about the cancer diagnosis and gave them an opportunity to ask questions. This was probably the reason for 22% of the siblings not asking their parents any questions about their brother's/sister's disease.

Table 6.16: Information needs of siblings

Questions that siblings asked parents	Percentage %
Why did get sick? (causes)	26
Isgoing to die? (prognosis)	12
Will I get the disease? (contagious)	7
Why is receiving so much attention?	8
Why can'tplay sport?	4
Why is loosing hair, vomiting, feeling sick? (side effects)	9
No questions	22
N/A (no siblings, young siblings with no language skills)	12

Table 6.16 reflects the information needs of siblings. In 66% of the families, siblings asked questions about various aspects of cancer. This was higher than the percentage of sick children (60%) who asked their parents about their disease. Siblings were curious about many aspects of the cancer trajectory, and therefore sought answers to questions which pertained to: the aetiology/causes of the illness (26%) and whether the disease was contagious (7%); the prognosis; whether their brother/sister was going to die (12%); why they (the sick child) had to suffer the disfiguring effects of treatment (9%); and, why their sick sibling was receiving so much attention (8%).

Family life inevitably changes temporarily and parents focused most of their energy on the sick child, which reduced the time they spent with other children. Many parents spoke about neglecting other children during the initial stages when treatment was intensive,

and when they were grappling with the diagnosis. One parent gave the example of the intense emotional disruption which ensued, where a sibling 'wished she could also get cancer because of the presents, staying at home and love'. Parents also expressed guilt related to missing sporting and other school activities which their other children participated in, because they had to be at the hospital to support the sick child during the treatment phase. The loss of attention and/or status was a theme which many researchers alluded to. Sloper (2000) found that this related to a number of factors: physical separations from parents caused by hospitalisations; emotional unavailability of a parent because of his/her distress; or, concentration on the ill child to the exclusion of the siblings. Separation from parents can be particularly difficult at a time when siblings are worried about the ill child and can add to feelings of rejection and loneliness (Sloper, 2000).

According to parents very few siblings reported negative attitudes and feelings towards their ill sibling. This was probably due to the fact that, in majority of cases, relatives and/or members of the extended family were available in the same household to provide care, comfort and support to siblings. Hence, the extended family structure provided for the support needs of the siblings and appeared to act as a moderating factor in preventing high levels of distress. Contrary to other research (Spinetta, 1981; Chesler and Barbarin, 1987; and Sloper, 2000) where a large percentage of siblings reacted negatively to changes in the quality of family life as a consequence of childhood cancer, most parents in this study reported that; siblings demonstrated great understanding and coped by obtaining support for their own needs from other sources.

Table 6.17 reflects the extent to which parents sought information about their child's illness from a number of sources. Upon diagnosis, parents are informed about their child's disease by the oncology staff. They are also provided with literature which they could read at their leisure. Thus, over half of the parents (56%) in this sample did not actively seek out additional information, nor did they avoid information on cancer. Chesler and Barbarin (1987) contend that upon diagnosis parents are overwhelmed by technical information about disease and treatments and the unfamiliar culture of the

medical system. Hence, not all parents want all the information immediately, as the information overload may add to their stress. Only 36% of the parents discussed their concerns with oncology staff after the initial discussion. Medical and psychosocial information serves to prepare parents and children to anticipate the course of the illness and the psychosocial consequences, thereby reducing feelings of uncertainty. Information helps to demystify the illness and affords them some sense of control. As parents learnt more about the illness, their feelings of anger and guilt lessened and they also found ways to restructure their lives to accommodate the cancer experience.

Table 6.17: Parents' sources of knowledge and information

Descriptions of information seeking behaviour	Percentage %
Talks to the oncology staff at the hospital	36
Talks to friends and relatives	12
Read books, magazines	20
Uses the internet	3
Multiple sources: books, medical staff, the internet	22
Consulted alternative healing sources: traditional healers, homeopaths, Reikie practioners	16
Did not seek any additional information except for what the doctor has given initially	56
Talks to parents of other children with cancer	64

According to most parents there was no need to engage with this topic further as doctors briefed them on a regular basis on the progress of their child. Many of them also felt helpless to influence the process and thus felt that if their information sources were censored it would be less distressing. Many parents preferred to adopt a passive attitude towards questions they had. Culturally most Black people do not question people in authority and the doctor's status is that of a person who has considerable authority by virtue of his/her academic achievements. Over half of the sample of parents also had a low level of formal education and therefore may have lacked the confidence and conceptual ability to engage with the complexities of cancer.

Some parents (16%) preferred to consult alternate healing sources as this was how they reacted to most ailments in their families. These parents reported consulting Reiki practitioners, traditional healers and homeopaths. All of these parents were advised by those practitioners to continue using the conventional medical treatment in conjunction with alternate healing methods.

Most parents (64%) relied on the parents of other children diagnosed with cancer for their information needs. In fact parents formed an informal support system, in the absence of a formal support group programme and in this manner helped each other with not only factual and logistical information, but also with their emotional needs. It was probably easier for parents to communicate with each other because of their shared experiences and the strong identification with their emotional needs. Many parents (73%) (appendix, 1.1) felt overwhelmed by the emotional experience of their child's illness and expressed the need for psychosocial services. They reported that they would participate in a support group programme if it did become available at a convenient location. Support groups could address many needs of the parents: it could serve as a forum to air some of their difficulties, receive advice and support and learn to communicate more openly.

A few parents (12%) had friends and relatives who were doctors, nurses or social workers and sought their assistance in understanding the cancer experience. Fewer parents (3%) consulted multiple sources such as medical journals, books, the internet and medical staff. The reasons given for such involvement in the topic were that they needed to know more in order to make appropriate decisions, handle questions which they may be asked by family and friends and learn about the long term consequences of cancer so that they could prepare their children to accept them. Twenty percent of the parents read articles in popular magazines, encyclopaedias and books written by people who have had first hand experience with the illness. Parents were able to identify with the experiences they read about, which helped to normalise their emotional journey and some of their difficulties. Only a very small percent of the parents (3%) used the internet in South Africa, which is still very much a third world country, where such technology is the privilege of a select few.

Table 6.18: Communication about the child's emotional experience

Communication variables	Percentage %
Enquires about child's feelings	73%
Enquires about whether the child is worried	82%
Expresses grief and worry in the child's presence	44%

Table 6.18 examined the verbal communication relating to the child's emotional state and the non verbal communication ie.; parents' expression of worry and grief. Many parents (73%), especially in the initial phase of treatment reported enquiring on a regular basis about their child's feelings. The rationale given was that many children did not openly volunteer information about their psychological wellbeing hence parents felt the need to assess how they were adjusting and to provide support when appropriate. Twenty seven percent of the parents who did not enquire about their child's feelings felt it unnecessary, because the child's behaviour did not indicate any form of distress. They asserted that if the child needed to share his/her emotions that the child should initiate the discussion. They also felt that the child should be treated as 'normal' as possible and argued that they would not ordinarily make such an enquiry.

Eighty two percent of the parents enquired about their child's worries. Most parents reported that their children adopted a very mature approach to the cancer experience and denied having any worries or complaints. Less than half (44%) of the parents expressed their grief and worry in the child's presence. Many of these parents admitted to crying in the child's presence especially in the hospital environment which provided a stark reality of life-threatening nature of the disease. Parents felt especially vulnerable and helpless when the child experienced pain and discomfort mainly as a consequence of treatment. Fifty six percent of the parents felt that if they openly expressed grief and worry it would have a negative impact on the child and may cause him/her to be discouraged about their prognosis.

Table 6.19: Communication between the child and parents about the death of fellow patients

Type of communication	Percentage %
Open communication	32%
Closed communication	68%

Table 6.19 reflects the type of communication which parents adopted when other children died. Most parents had experienced or heard from their children about fellow patients who had died in hospital. Thirty two percent of the parents spoke openly to their children about these deaths. Many of them did not wait for their child to initiate the discussion as they felt that open communication facilitated the expression of their child’s emotional needs and took the opportunity to deal with grief and talk about their anxieties. While parents spoke openly about the death of other children they avoided discussing the possibility of their own child’s death, but instead emphasised the differences between the illness trajectories of the deceased children and their child. This stance allowed children not to loose hope. Many parents commented about how ‘well’ their children accepted and coped with the death of fellow patients.

Other parents (68%) were very guarded about what they said about fellow patients who died as they feared it was a heavy burden to bear and would unduly distress their children. These parents avoided acknowledging death, and discussing them openly with their children. The reasons cited by these parents were that the experience was so overwhelming and scary that they felt almost impotent to engage with these issues. Experiences with fellow patients are generally reminders of the uncertainty, which characterises this illness. This usually had a distressing effect on parents for a period of time until they made sense of it for themselves. Children inevitably experience the death of other children whom they have befriended in the hospital wards. These deaths force them to recognise and question the seriousness of their diagnosis, and their own mortality. Many parents did acknowledge that despite their attempts to censor communication about death related issues, their children openly resolved their concerns in discussions with fellow patients, nurses and volunteers.

6.3 PSYCHOLOGICAL ADJUSTMENT TO ILLNESS

What is the intensity of the emotional reactions of the sick child and their parents?

The literature review chapter highlights the lack of consistency across studies that exist with regards to the adverse psychological impact of cancer on children and their families. The purpose of this section is to investigate the prevalence of psychological problems experienced by children with cancer and their parents during the treatment phase. This section, examines the behavioural problems which parents report that their children experienced, depression and anxiety variables which children themselves reported, as well as the levels of distress which parents report experiencing. Statistical analyses using Pearson product moment correlations, cross tabulations and the chi square test failed to show any associations between race and gender variables among the children as assessed by the CDRS-R and SCAS.

Table 6.20: Emotional/behaviour problems reported by parents of children diagnosed with cancer

Problems	5 to 7 years n=17 %	8 to 12 years n=63 %	13 to 16 years n=20 %	total n=100 %
Sleeping problems	17,6	25,4	20,0	23
Eating problems	29,4	34,9	35,0	34
Bedwetting	29,4	17,5	5,0	17
Problems at school	47,1	44,4	25,0	41
Socialisation with friends	52,9	44,4	20,0	41
Non-participation in sport	47,1	58,7	40,0	53
Severe pain	58,8	42,9	55,0	48

Table 6.20 presents the percentages of children according to their age groups who present with behavioural problems. Parental reports on behavioural parameters were assessed as they could be conceived as indicators of emotional problems. In general, parents assessed their children as cheerful and mildly anxious when they had to endure painful procedures.

Parents also confirmed that the main behavioural difficulties experienced by children were problems related to schooling, severe pain, being isolated from peers and having difficulty maintaining old relationships and not being able to participate in sporting codes which required physical exertion. According to Sawyer, Antoniou, Toogood and Rice (1997), the prevalence of problems experienced by children with cancer of different ages may vary, as well as the number of problems experienced by children and parents varies at different points in time.

Assessment of children's mood and affect based on the Children's Depression Rating Scale-Revised

The affective responses of children together with the mean and SD are presented in table 6.21. A score of 39 and below was attained by 7% of the children mainly between 5 and 7 years of age (table 6.22). Such scores were generally low for clinical populations and may be associated with denial. Children with cancer and other serious chronic illnesses tend to use denial as an adaptive mechanism to block out depression and anxiety in order

Table 6.21: Affective responses of children based on the CDRS-R

Categorical breakdown of CDRS-R scores	n=100 (%)
Depression extremely rare (≤ 39)	7
Depression unlikely (40-54)	25
Depression possible (55-64)	52
Depression likely (65-74)	12
Depression very likely (75-84)	3
Depression almost certain (≥ 85)	1
CDRS-R scores	
Mean \pm SD	55,8 \pm 11,7
Range	20 – 85

to deal with the practical demands of the illness. Parents and medical staff, who encouraged children to use distractive techniques to maintain a positive disposition, also reinforced this. Fifty two percent the children attained scores, which clustered around the

mean (55,8 ±11,7) and fell within the range of possible depression. Although depressive symptoms were not very common in this sample, 16% of the children had scores consistent with “likely”, “very likely” and “almost certain” suggestive of a major depressive disorder. Depressive symptoms were more prominent amongst adolescents than younger children (table 6.23).

Table 6.22: Distribution of scores on the CDRS-R according to age

Categorical breakdown of CDRS-R scores	Age		
	5-7yrs	8-12yrs	13-16yrs
	n=17 %	n=63 %	n=20 %
Depression extremely rare (≤ 39)	29,4%	3,2%	0%
Depression unlikely (40-54)	58,8%	22,2%	5%
Depression possible (55-64)	11,7%	68,3%	35%
Depression likely (65-74)	0 %	6,3%	4%
Depression very likely (75-84)	0 %	0 %	15%
Depression almost certain (≥ 85)	0 %	0 %	5%

Table 6.23: Children's rating of the symptom scales on the CDRS-R

Depression Variables	5 to 7 n = 17 %	8 to 12 n = 63 %	13 to 16 n = 20 %	total n=100 %
Impaired schoolwork	29,4	42,9	40	40
Difficulty having fun	47,1	41,3	35	41
Social withdrawal	41,2	21,7	40	35
Sleep disturbance	23,5	20,6	40	25
Appetite disturbance	52,9	38,1	30	39
Excessive fatigue	47,1	25,4	25	29
Physical complaints	29,4	27,0	20	26
Irritability	23,5	22,2	20	22
Excessive guilt	0	1,6	10	3
Low self-esteem	11,8	28,6	40	28
Depressed feelings	17,6	25,4	40	27
Morbid ideation	0	4,8	15	6
Suicide ideation	0	1,6	0	1
Excessive weeping	17,6	20,6	5	17

None of the children scored within the moderate to severe range of the symptom category scales. According to the norms of the CDRS-R, scores on these scales are rare. Thus, only symptom scales, which were scored as ‘clinically significant’, were interpreted and reflected in table 6.23 and table 6.24. There was some discrepancy between children’s ratings of themselves and parents’ rating of their sick children on the symptom scales of the CDRS-R. Parents’ (table 6.24) consistently rated the individual symptom scales lower than their children (table 6.23).

Table 6.24: Parent ratings of their children on the symptom scales of the CDRS-R

Depression Variables	5 to 7 n = 17 %	8 to 12 n = 63 %	13 to 16 n = 20 %	total n=100 %
Impaired schoolwork	20,4	30,9	20	35
Difficulty having fun	20,1	23,3	30	39
Social withdrawal	20,2	12,7	32	30
Sleep disturbance	20,5	15,6	20	19
Appetite disturbance	52,9	48,1	38	42
Excessive fatigue	35,1	20,4	15	29
Physical complaints	16,4	25,0	18	26
Irritability	12,5	22,2	20	22
Excessive guilt	0	0	5	1
Low self-esteem	5,8	20,6	40	28
Depressed feelings	4,6	21,4	40	25
Morbid ideation	0	2,8	10	4
Suicide ideation	0	0	0	0
Excessive weeping	10,6	18,6	2	14

The means and standard deviations for the depression scales are presented in table 6.25. Children diagnosed with cancer, struggled most with: schoolwork, having fun, eating habits, irritability, self esteem issues and feelings of sadness. About 40% of the children mainly between the ages of 8 and 16 years experienced some problems in the form of decreased interest and enthusiasm as well as difficulties concentrating on their school work. In an independent rating (table 6.24) parents, confirmed that 41% of the children experienced problems at school. These findings are also consistent with other studies cited by Bessel (2001): Klopovich, Hearn and Lansky (1982); and O’Connor and Blech,

(1992) which found that children with cancer were at risk for school adjustment difficulties due to absenteeism. In addition Deasy-Spinetta (1981) also found that changes in social interaction were also contributing factors to children's school related problems. Older children and adolescents were more successful than younger children in concealing their school related difficulties from their parents. These difficulties were not related to attention deficit difficulties or distractibility. Problems related to schooling included absenteeism for long periods of time, many children reported repeating a year despite attending hospital based school programmes. Thus, impairment in school functioning manifests diminished performance, which improves as the child attends school more frequently and the treatment effects reduce or subside. Bessel (2001) asserts that school experiences are a strong factor in providing a child with a feeling of normalcy.

Table 6.25: Means and standard deviations of depression variables on the CDRS-R

Depression Variables	mean	SD
Impaired schoolwork	3,49	1,759
Difficulty having fun	4,47	1,611
Social withdrawal	2,47	0,622
Sleep disturbance	2,31	1,02
Appetite disturbance	3,02	0,709
Excessive fatigue	1,38	0,648
Physical complaints	2,89	1,52
Irritability	3,31	0,895
Excessive guilt	1,04	0,243
Low self-esteem	3,31	1,457
Depressed feelings	3,43	1,346
Morbid ideation	1,06	0,239
Suicide ideation	1,01	0,223
Excessive weeping	3,01	0,976

Anhedonia is commonly experienced in children diagnosed with depression. This may be characterised by a lack of interest or boredom in activities they previously enjoyed. While 41% of the children scored high on this symptom scale, unlike clinically depressed children, their disease and treatment often imposed restrictions on them having fun. Physical limitations as a result of disease may restrict children's freedom and hinder them

from participation in fun activities, eg. hospital admissions, confinement to bed, being nursed in isolation, inability to participate in certain sports, not attending friends' parties and being unable to attend school and other extra curricular activities. In fact this was corroborated by parents who asserted that 41% of the children found that not being able to socialise with their friends and being unable to participate in sport (53%), stressful. These restrictions also accounted for much of the irritability children experienced. Such irritability and frustration normally lasted for short periods of time.

It is not uncommon for children on treatment to experience changes in their appetites, 39% of the children reported such changes. Parents tended to report that more children (41%) had appetite problems. Nurturing generally takes place through food and when children stop enjoying their food or reduce their intake parents naturally feel implicated in this activity. Additionally, within collectivist cultures, health is equated to being well fed. One mother reported feeling really ostracised and inadequate as many people commented on her daughter's weight loss, as she was 'made to feel that she was not taking good care' of her sick child.

Most adolescents in the sample were generally confident and comfortable with all other aspects of their development, except that they described their body image and sense of attractiveness in a negative manner. Adolescents (40%) experienced major problems with self-esteem issues. Bodily changes such as alopecia, amputations, skeletal abnormalities, weight gain/loss and acne were all related to decreased self-esteem and thus also resulted in depressed feelings which 40% of adolescents reported. Kameny and Bearison (2002) reported that adolescents with cancer worry about physical pain and loss of physical attractiveness. Black adolescents reported that they were often seen as different from their peers because their hair became straight instead of the original curly texture. While some adolescents preferred this and saw it as one of the advantages of having cancer, others were not as comfortable especially when this difference made them more visible and open to stigmatisation. Adolescence is a time when there is great concern and attention given to appearance and self-improvement. Turner in 1984 and later James in 1993 concluded that the child's 'body is drenched with symbolic influences' and

therefore constitutes an important element through which children create their identities (Langton, 2000). Hence, deviations from stereotypical normative notions have the potential to create anxiety.

Assessment of anxiety based on the Spence Children's Anxiety Scale

Table 6.26: Distribution of scores on anxiety variables according to age groups

Anxiety Variables	5 to 7 years n = 17 %	8 to 12 years n = 63 %	13 to 16 years n = 20 %
Panic/agoraphobia	17,6	19,1	15,0
Separation anxiety	88,3	49,2	25,0
School phobia	11,8	15,9	35,0
Obsessive compulsive	3,0	6,3	10,0
Physical injury fears	11,8	30,1	45,0
Generalised anxiety	30,3	39,7	29,0
SCAS total scores			
Mean (SD)	28,4(15,8)	38,85(18,6)	31,62(17,7)

The mean anxiety scores for each age grouping (table 6.26) on the SCAS do not deviate significantly from the non-clinical norm group. It can thus be inferred that children diagnosed with cancer do not suffer from disabling levels of anxiety and as such are no different from children who do not carry a diagnosis of chronic illness. However, if the means and standard deviations for each age group are compared, the 8-12 year olds showed higher levels of anxiety than the younger children and the adolescents. On the individual scales of the SCAS separation anxiety and fears of physical injury featured more prominently in comparison to the other subscales. Separation anxiety was a major concern for 88,3% of children between 5 and 7 years of age; however, as children became older they coped better with being separated from primary caregivers. These findings are consistent with developmental theories which suggest that children at this stage have not yet developed the confidence and autonomy to be left on their own, especially in unfamiliar environments.

Physical injury fears were endorsed by 45% of the adolescents as anxiety provoking. Injury relates to body image disturbances, which are of primary concern not only for adolescents with cancer, but also for healthy adolescents, however, these anxieties may become exacerbated by their already compromised physical appearance.

Some of the children's anxieties could also be inferred from the question pertaining to 'negative experiences about cancer' (appendix 1.1). Only 4% of the children endorsed the fear of death as a concern. Other issues such as admissions to hospital and treatment related issues such as chemotherapy and invasive medical procedures aroused a fair amount of anxiety and discomfort.

These disruptions had a negative impact on social interaction and participation in sport and other extra-curricular activities. Many experienced some difficulty with re-entry into the school system as some encountered teasing. Some of the Black children reported that their friends thought that they had AIDS and were concerned about contracting the disease. The HIV/AIDS pandemic has been the focus of many educational and preventative programmes children were thus more aware of it as a serious illness and not as familiar with cancer and therefore confused the two. Their cancer diagnosis made many children feel 'different' and created social stigma, which arose out of fear and misinformation about cancer. Poor peer acceptance was also related to self-perception problems.

From the literature (Sourkes and Proulx, 2000; and Bennet, 2003) on developmental differences in children's understanding of illness, it is clear, that young children have not yet developed the cognitive skills to fully understand and appreciate the potential side effects or the long-term consequences of having an illness such as cancer. Therefore their self-reports indicated less distress and better adjustment. Most of the children in the study did not have serious problems. The general assumption is that time heals and as the period of remission lengthens the stresses associated with the illness will also reduce significantly or dissipate altogether. This proved not to be a consistent pattern in this study as correlations between emotional variables and duration since onset of illness

failed to show any relationships. In fact, Van Dolgen-Melman (2000) commented that adjustment problems seemed to increase after treatment ceased.

Assessment of parental psychological functioning based on the General Health Questionnaire

The mean scores of parents GHQ-28 are reflected in table 6.27. The GHQ28 served as a score was derived from the sum of the four subscales and a score of 5 or more on the individual subscales was considered to reflect ‘psychiatric caseness’. The total mean score (26,5 ± 8,6) is not indicative of severe disabling psychological distress. Perhaps such distress might not even be acknowledged as a ‘pathological’ or ‘aversive’ state to be avoided. Much of the distress was temporary (and appropriate) and did not warrant psychosocial intervention. In fact some parents’ conceptualised the cancer experience as a time of suffering thrust upon by a higher power to test one’s faith and moral fibre.

Table 6.27: Means and standard deviations of parental distress based on the GHQ-28

Distress variables	mean	SD
Total Score	26,5	8,6
Somatic symptoms	8,5	3,6
Anxiety & Insomnia	9,7	4,1
Social dysfunction	3,5	3,2
Severe depression	4,6	1,8

All the parents discussed how emotionally overwhelming the cancer diagnosis and treatment phase had been. Many parents also admitted to feeling some degree of guilt. Parents also felt guilty about not taking their child’s early expression of symptoms too seriously and regretted delaying the process. Some attributed the child’s cancer to misfortunes and magical causes and hence felt this was a form of ‘punishment’ from the ‘gods/ancestors’. Others felt that their child may have inherited the disease from one or other parent. In fact a few parents had asked the doctors to clarify whether they could have caused their child’s illness. Many parents spoke about trying to find out ‘what they

had done' others had asked themselves 'why me' or 'why my child'. Chesler and Barbarin (1987), categorised these questions as 'existential stress' and suggested that at one level the quest may represent a serious intellectual search but more often it represents a cry of pain and anguish, of confusion and outrage. This is a further indication that some of the parental emotions may be masked. By the time of the interview all the parents had resolved these guilt issues and accepted that there were no clear answers. Some of them used spirituality and ritualistic behaviours to understand their present circumstances.

Most parents expressed concerns and anxieties over various aspects of their child's treatment success, survival, physical side effects, school performance and uncertainty about what the future held. Parents also expressed great anxiety about their ability to provide adequate support to their children during the treatment phase. A few parents were also concerned about missing covert symptoms of distress as they felt that their children were not very vocal in expressing discomfort and distress.

The insomnia and anxiety as well as the somatic symptom scales were elevated and reached caseness. A qualitative item analysis of the statements endorsed by parents provided an indication of specific difficulties, which they had experienced. On the anxiety and insomnia scale (mean $9,7 \pm 4,1$) they had complained of the following: "loosing sleep because of worry, difficulty remaining asleep, feeling constantly under strain, feeling overwhelmed ('found everything getting on top of you') and feeling nervous and high-strung". The prevalence of these problems has been supported by many studies. Sawyer, Streiner, Antoniou, Toogood and Rice (1997), reported that after diagnosis, parents tend to experience a high level of strain, anxiety and insomnia but this distress declines and stabilises over the first year. Parents displayed a high level of commitment in helping their children to deal with the illness experience and therefore tried as far as possible to remain unemotional and strong in the presence of their children

The somatic symptom scale had a mean score of 8,5 (SD = 3,6). Statistical analyses using a contingency table and a Spearman rho correlation co-efficient, revealed a moderate association ($r = 0,52$, $p < 0,001$) between somatic symptoms and the race variable. Black

parents scored consistently higher than White parents on this subscale. Within the Black culture in South Africa emotions are generally expressed and experienced in somatic terms. In fact many of the indigenous linguistic systems do not have expressions for 'depression' and 'anxiety'. The items frequently endorsed on the somatic symptom scales were: "not feeling very well, feeling run down, feeling ill, pains in the head and pressure in the head".

6.4 COPING WITH CANCER

What specific coping strategies do children suffering from cancer use to cope with stressful aspects of illness and treatment?

The KIDCOPE was administered to examine what aspects of the cancer experience children found stressful and the strategies they used to cope with these stressors. The influence of gender, age and race were tested for significance using a contingency table and Pearson product moment correlation coefficient. Both race and gender showed no significant associations, hence table (6.28) summarises the coping strategies used by children according to age.

Children were asked to identify illness related stressors and the associated distress they experienced as a consequence of it. Many common themes were derived despite children not using the exact terminology to express their distress. Older children were able to cluster and categorise their thoughts often using medical jargon to express themselves while younger children tended to be more descriptive. Such use of language appeared related to cognitive development and language acquisition as opposed to illness related variables or psychosocial conditions.

Significant stressors for children were long periods of in-patient treatment, repeated hospitalisations due to relapses and complications, the distressing side effects of treatment, invasive medical procedures, absences from school/repetition of school year, severe pain and the death of other children. Seventy two percent of the children reported

that these stressors made them ‘nervous’ or ‘anxious’, while 43 % felt ‘sad’ or ‘unhappy’. Only 3% of the children felt ‘anger’ as a result of illness related stress. This may yet again be an instance of the defence mechanism of ‘denial’. Spirito, Stark, Gil and Tyc (1995), assert that understanding what chronically ill children find stressful besides pain and identifying strategies they use to cope are important for intervention.

Table 6.28: Distribution of coping strategies employed by children according to age (based on KIDCOPE).

Coping Strategies	5 to 7 years n = 17	8 to 12 years n = 63	13 to 16 years n = 20
Distraction	24,6%	20,9%	18,0%
Social withdrawal	22,4%	20,3%	25,0%
Cognitive restructuring	31,2%	56,9%	89,9%
Self-criticism	7,6%	9,2%	44,2%
Blaming others	49,7%	4,6%	4,3%
Problem solving	23,5%	64,3%	95,0%
Emotional regulation	26,0%	42,3%	42,6%
Wishful thinking	35,2%	57,1%	28,5%
Social support	67,1%	68,3%	60,0%
Resignation	20,6%	35,4%	58,2%

According to the Kidcope norms (Spirito, Stark and Williams, 1988), most children in the study proved to be psychologically healthy and made use of several coping strategies to adjust to their illness. The frequency with which each coping strategy was used is reflected in table (6.28). The consistent age effect was that adolescents used cognitive restructuring; problem solving and social support more than younger children did, with the youngest group of children, 5 to 7 years, using blaming more. During periods of stress 89,9% of the adolescents focused on trying to see the good side of things or concentrated on a positive outcome. Many of the adolescents found repeated hospitalisations and chemotherapy very stressful and anxiety provoking but they rationalised these events as leading to an improved prognosis and longevity. One adolescent articulated this as ‘short term pain and suffering for long term gain’. Ninety five percent of the adolescents used active problem techniques to gain some control over their disease and its treatment. They

asked fellow patients and medical staff for additional information in areas where they lacked sufficient clarity or alternatively they asked them to describe certain procedures.

The results suggest that 58,2% of adolescents used 'resignation', (ie., they just accepted the problem because they could not do anything about it) as a coping strategy more than younger children. This finding is supported by Enskar et al. (1997), who contend that, adolescents are able to understand the physiological processes underlying the disease, and as such are able to comprehend the potential long and short-term *sequelae*. Schlowner (in Spirito et al., 1995) postulates two explanations for the use of resignation: (i) may reflect a more mature understanding and the attainment of the formal operational stage of cognitive development, which is associated with the realisation that nothing can be done about certain problems, and/or (ii) it is related to greater duration of illness in adolescents than younger children.

Many children showed the ability to reflect on and understand the reasons for their situation and found that having information and supportive relationships helped them cope. Parents reported the illness experience had resulted in some positive outcomes in their children, such as increased confidence, greater independence and maturity. This is consistent with Lazarus and Folkman's (1984) theoretical model of stress and coping, which emphasises the importance of problem focused coping strategies. Sloper (2000) reports that self-reflection and self-understanding are important in resilience and the existence of a positive support system in the family and the child's wider external network has been identified as an important protective factor in children who appear to be resilient to the effects of stressful life events.

How do parents cope with the multitude of stressors and problems resulting from their child's illness?

Family assessment measures provide information on the family's resources, priorities, concerns and unique characteristics. The results from the FCOPES (table 6.29) and the CHIP (table 6.29) revealed mean scores within the normative range and thus indicate that

while these families experienced the cancer diagnosis as stressful and demanding they: (a) adapted by acquiring and using resources from both within the outside the family boundaries; and, (b) used effective coping strategies such as mobilising and acquiring personal and social support and cognitive strategies such as reframing and positive appraisals.

Table 6.29: Problem solving attitudes and behavioural strategies used by parents to cope with their child's cancer (based on FCOPES)

Coping skills	mean	SD
Acquiring social support	28,76	8.447
Reframing	29,06	7,258
Seeking spiritual support	17,26	6,668
Mobilising family to acquire & accept help	14,47	3,693
Passive appraisal	13,51	4,466

According to the parents in this study, the stressors which they experienced, were multiple and ongoing and varied over time. The stressors, which they reported as most challenging were:

- At the time of diagnosis, many parents experienced some difficulty comprehending the meaning and seriousness of the situation either due to intervening emotions or low levels of education and illiteracy.
- The uncertainty of whether the child will live or die.
- The high technology environment of the hospital was intimidating as well as some of the medical procedures difficult to grasp.
- Treatment and the side effects caused both physical and emotional pain in their children. Parents reported that seeing their children in such pain was often heart-wrenching and precipitated overwhelming feelings of helplessness, guilt and inadequacy.
- The cancer experience was fraught with exacerbations. Hence deterioration in the child's condition necessitated the intensification of treatment and often hospitalisation. It not only altered the emotional status of the family but also

caused an upset in the equilibrium in the home and as such living arrangements and roles, which had to be renegotiated.

Table 6.30: Adaptability of various coping styles (CHIP)

Coping styles	means	SD
I. Integration, co-operation, optimism.	45,36	7,363
II. Support, self-esteem, stability	28,06	8,841
III. Medical communication & consultation	17,61	4,855

Coping strategies (table 30) reflected in Scale I of the CHIP (maintaining family integration, co-operation and an optimistic definition of the situation) were used frequently and perceived as most helpful by the majority of parents. Parents who used this coping pattern emphasised doing things together as a family unit, strengthening family relationships and developing and maintaining a positive outlook on life in general and specifically when a member has a chronic illness (Figley & McCubbin, 1983). Many parents' attitudes were exemplified in the quote 'we tried to keep family life normal and positive after the diagnosis'. Concerted efforts were made by families to normalise the situation. Approximately 75% of parents received considerable help from family members (eg. spouses/partners, grandparents, their own siblings and their older children) who took care of healthy siblings, the household needs and also provided some respite from the care of the sick child. Such help from family members freed parents from taking on additional chores and gave them the psychic energy to maintain an optimistic attitude and consequently allowed them to meet members' needs for intimacy, empathy, personal affirmation and support despite living through the distress.

Parents reported that their partners and their parents were their primary sources of support in coping with their child's cancer diagnosis. Mothers (48%) generally initiated the conversation with their partners. According to the mothers most of their partners provided some emotional support in form of reassurance, willingness to assist with household chores and the management to healthy children. However, most fathers (52%) experienced great difficulty listening to mothers' expression of anxieties and feelings and

often responded by avoiding engaging with those emotions. It appeared that fathers were uncomfortable with their own feelings as well as only 15% of them expressed some emotions overtly. Hence, it appears that many fathers may have internalised their negative emotions, which has the potential to manifest itself at a somatic level. These findings offer support for the notion that caring and the expression of emotions is socially constructed as an area of female competence. Additionally, cultural expectations demand that men “present themselves as the rock in the crisis, calm and clear-thinking among the supposed wild running emotions of women” constraining men’s own needs for emotional expressiveness (Reay, Bignold, Ball, & Cribb, 1998). Males seem to be trapped in stereotypical and normative values, which place restrictions on the expression of their feelings and label male displays of emotion as a demonstration of weakness. It also attests to the unequal power imbalances, which exist between men and women and the damaging consequences (emotional distancing and interpersonal friction) for both sexes that often ensue. While some men and women succeed in disrupting normative and stereotypical constructions, most South Africans appeared to adhere to traditional roles. Overall, very few parents described marital difficulties precipitated by the diagnosis instead most parents reported that their child’s illness had strengthened their relationship. Those parents who reported marital stress admitted to experiencing communication difficulties prior to the diagnosis. None of the single mothers in the study group attributed their divorce or separation to their child’s cancer. The literature base constantly makes reference to the importance of the quality of the marital relationship before the diagnosis. This was confirmed in this study as well as families with pre-existing problems generally continued to experience difficulties as a function of a structurally weak and taxed system

Despite concerted efforts to ‘make the best of a bad situation’ most parents in the study, struggled to improve the quality of their lives during this phase of their child’s cancer as life was dominated by hospitalisations, changes in living arrangements, financial pressures and a range of negative emotions.

Scale III (comprehension of the medical situation) on the CHIP (table 30) was also found to be very helpful. This coping strategy relates to parents’ ability to develop relationships

with other parents who have a child with the same illness and with medical staff and in this way to try to understand and master the medical information needed to care for their sick child. Parents reported that they acquired social support by developing relationships with other parents within the treatment context. These relationships appeared to develop spontaneously and were generally maintained through the course of treatment. Such relationships not only served as an important source of emotional and social support but also satisfied the medical informational needs of most parents. Other parents were an important coping resource as they were able to share feelings of joy, pain, hope and despair in a manner that was non threatening and uncritical of their vulnerabilities. These relationships also provided insight as to how other parents incorporated the existential meaning of childhood cancer into their own lives and encouraged parents who were struggling to make sense of the meaning and relevance of their child's cancer to discover more effective answers.

Respondents reported high levels of satisfaction with the understanding and support they received from the medical staff. Parents portrayed the medical staff as highly competent and did not report relational difficulties. Medical staff provided parents (who were present at the treatment units) with descriptive information on treatment and the possible physical implications of these procedures. Parents reported that this information helped them to handle the situational specific stressors, reduced their anxiety and also improved their emotional and functional coping. This form of active appraisal and reframing is consistent with Leventhal's self-regulation theory which contends that the provision of concrete, objective information to individuals during stressful encounters assists them in creating cognitive schemes that are analogous to the real life event (Bennet, 2003).

Spiritual support was sought by many parents to gain explanations for their child's cancer diagnosis. Families in this sample scored on the average higher than the normative group, and therefore relied fairly heavily on spiritual support as a coping skill. Parents who adhered strongly to a particular faith often appraised the situation as 'God's will' and accepted their child's cancer diagnosis with resignation. However, this did not deter them from being hopeful and by the same token, believing that divine intervention will aid in

curing their child. On the 'passive appraisal' subscale, parents indicated active levels of perceiving and addressing difficulties in their families. A frequently used coping skill, was 'reframing'. Families did not conceptualise the cancer diagnosis as a disaster which was unfair and beyond their control, instead they drew on the optimism and hope which the medical staff encouraged and adopted a positive attitude about 'beating cancer'. Many parents also sought comfort through prayer. Hussein-Rasool (1995) asserts that it is important to give people the opportunity to define their problems from their own perspective and within their socio-cultural context.

Unlike scales I and III, which are active problem focused skills, scale II (maintaining social support, self-esteem and psychological stability) represents emotion focused coping skills and is linked to diversionary and compensatory strategies. Although parents did use these strategies they did not find them very helpful in coping with stressors related to their child's cancer.

The influence of socio-demographic variables such as race and educational level of parents was examined using the Pearson product moment correlation coefficient. The following trends could be traced:

- There were no significant differences between Black and White parents in their problem solving attitudes and the behavioural strategies adopted as reflected by scores on the FCOPES and Scales I and II on the CHIP.
- White parents appeared to use coping pattern III (understanding the medical situation through communication with other parents and consultation with medical staff) on the CHIP more than black parents did and found it more helpful. There may be several explanations for these differences. It may again reflect some elements of black culture, which promotes the unquestioned respect and acceptance of knowledge and wisdom from authority figures or the lack of competence and confidence to engage with medical staff as a function of low levels of formal education. In addition many black parents had little contact with other parents as many of them were not able to spend long periods of time with their sick children. Many black South African children do not have the luxury of

their parents being present at the hospital to support them during their cancer treatment, and sometimes have to settle for weekend visits. This further reduces their chances of contact with doctors and other parents. Ultimately the doctor is the path to cure and as such must receive respect. Dissatisfaction with one's medical care is often very difficult under circumstances of such dependency. When coping with such a life-threatening disease as cancer, parents may find it essential to maintain a 'blissful ignorance' or unquestionable faith in the expertise of the medical staff.

- Parents with a higher educational level used 'reframing' slightly more than parents of a lower educational level. There were no significant differences in the other coping skills.

CHAPTER 7

CONCLUSIONS AND RECOMMENDATIONS

7.1 CONCLUSIONS

A diagnosis of paediatric cancer shatters pre-morbid stability, instantly altering goals and expectations and testing the bounds of meaning and structure. The threat of death adds a new distinctive dimension and heightens debates about the meaningfulness of life and after life. Childhood cancer is clearly outside the realm of the ordinary family life cycle and the usually anticipated experiences for both children and their families. But, whether or not it is interpreted, as a traumatic experience is dependent on many factors. One cannot fully appreciate how people react to illness, death or misfortune without a proper understanding of the type of culture they have grown up in or acquired, as also, the lens through which they perceive and interpret the world. It is thus imperative to examine the social organisation of health and illness in society, the ways in which people become recognised as ill and the ways in which they present their illness to others. Against that backdrop, alternate healing systems such as homeopathy, herbalism and spirituality cannot be ignored.

A significant proportion of children with cancer and their families experience significant levels of psychological distress, so we are informed by psychosocial oncology. The question that arises is: whether children and their families actually perceive themselves as suffering from psychological distresses thus requiring 'psychological intervention'. Most children afflicted by cancer and their families were reasonably healthy in psychosocial terms. They presented as 'normal' people experiencing a major and prolonged trauma. Contrary to the 'deficit' perspective, in this study psychopathology was not a standard outcome for parents or children diagnosed with cancer. Nonetheless, the cancer experience did have a definitive impact on every facet of their lives. The diagnosis

immediately changed the homeostatic balance of the family and challenged their functional ability to continue as they had in the pre-illness state. Those families that redefined 'normalcy' to incorporate the illness generally coped more efficiently. Antonovsky (1988) uses the concept 'salutogenesis', which focuses on how individuals and families stay healthy instead of why they become ill. By studying these properties one can examine characteristics, which contribute to greater positive outcomes in childhood cancer.

Although childhood cancer has been described as a shared stress in which the family bares the brunt of the emotional burdens associated with treatment and care, the manner in which it impacts on the child was certainly different to the rest of the family. Chesler and Barbarin (1987), eloquently articulate the experiences of children in the study and children in general. According to them, "...of all the treatment related issues that children with cancer find difficult, the unremitting, continuous and prolonged course of treatment having to deal with it from week to week is most debilitating, there is no respite, no escape from the inevitable series of events". While some children received a lot of support others were less fortunate. For many South African children living issues are not always renegotiated, due to poverty, scarce living resources, reliance on public transport, inability to obtain flexibility at the work place, unavailability of finances, etc. These children do not have the luxury of parental presence on a regular basis and often have to settle for weekend visitation. Those parents bear the additional burden of guilt at not being at their children's side

Most of the child respondents did not have serious problems such as overt signs of either depression or disabling anxiety. Communicating about the illness was, however, generally limited to physiological and medically related matters, whilst emotional issues were rarely articulated. Despite having to adjust to a whole range of bodily changes, withdrawal from society and deal with being isolated from their peers, their overt distress levels were low. There is a possibility that children were in fact depressed and masked it through denial or were creating a façade in order to protect their families and themselves. The general assumption and philosophy adopted by most parents and children and

reinforced by staff was that time heals and as the period of remission lengthens the stresses associated with the illness will also reduce significantly or dissipate altogether. This notion does in fact seem overly optimistic as Van Dolgen-Melman (2000), commented that adjustment problems seemed to increase after treatment ceased.

There were great discrepancies in the amount of information, which parents themselves imparted to siblings. Such a stance can potentially alienate healthy siblings and exacerbate their distress, as the provision of information serves the important function of enabling them to understand what is going on in their lives and helps them appreciate that the disruptions of routine are temporary. Information is also an important empowering tool for both children and their siblings, with it they can explain to others what is going on in their family. Parents experienced difficulty communicating with healthy siblings about the illness. A psychological assessment of siblings' emotional adjustment and coping was beyond the scope of this study, hence it was impossible to ascertain what impact parental communication or the lack thereof had on siblings. Honest discussion can serve a protective or preventative function, in that, it can dispel fears and fantasies and help to express stressful emotions and provide reassurance and security (especially instances when more attention is given to the sick child).

The health care team was an important source of information for most families. Those interactions were characterised by support, reassurance, realistic hope, and ready accessibility to assistance and respect. Effective communication between parents and the oncology team is essential. Accurate information helped parents understand each phase of the treatment programme and empowered them to take decisions that are in the best interests of the child. Whether or not parents used this support system depended upon how parents perceived their value and how it affected their self-esteem. While some parents sought frequent consultations with the medical staff on a range of issues, others (mainly Black parents with lower educational status) were satisfied with the information imparted to them and therefore resisted further contact with the team for fear that their conduct may be construed as contempt for authority structures.

Families' beliefs about the cause/s, treatment and prognosis of cancer are influential in psychological adjustment as well as the coping strategies used to deal with the illness. These beliefs may be firmly embedded within the cultural context. Theories of cancer aetiology are linked to general cultural explanations for health and illness and have an influence on the expressions of stress as well as the enactment of coping strategies. Gochman (1992) argues that in both the developed and developing countries, cognitions about diseases reflect an intertwining of folk beliefs with beliefs that are congruent with, or derived from, biomedical technology.

Parents expressed great confidence in the high standard of medical care that their children were given. There was without doubt some level of defensive idealisation as parents needed to believe that they were receiving the best care available and that technically, everything was being done. This idealisation would not have been sustained if the standard of the paediatric oncology service were not in reality consistently good. Regardless of the availability of high standards of medical care, there were culturally driven differences in the nature of interaction between medical staff and patients and their families. White parents sought more information and dialogue with staff as compared to Black parents.

Parents employed active efforts to manage the stress and hardships associated with having a child diagnosed with cancer, while simultaneously coping with normative life cycle issues, changes and sources of stress in the family. Their activism usually involved efforts to remain optimistic, hopeful, supportive and to normalise the sick child's and the family's life. While the negative consequences of cancer were obvious, there were also positive consequences eg. the adaptive functioning in the face of a major stressor, appeared to strengthen and promote the physical, emotional and social growth and development of the entire family including the sick child.

Social support, appraisal and family coping strategies are important areas of strength which may mediate stress in families of children with cancer and promote adaptation. An important component of effective coping is the family's ability to use relationships

for emotional support. Parents who felt that they coped well, spoke about remaining optimistic by focusing on positive thoughts, maintaining a relatively normal personal and family life and receiving emotional and instrumental support from family and friends. Children and families were also on the receiving end of prejudice and ostracism. Although the literature indicates that cancer, unlike AIDS is one of the illnesses where there is no stigma, this was not entirely true for South African children. Both parents and children reported that their social networks did not always understand the differences between the two illnesses and generally equated them. This led to rejection, reduced self-esteem and isolation of both the patient and their families. Despite biomedical evidence to the contrary people thought and acted as if cancer was contagious. This rejection was based on ignorance and personal anxieties.

The prevalence and use of coping mechanisms may differ across cultures. White families relied more on social resources outside the family (such as friends and live-in housekeepers) whereas Black families had strong familial support networks. According to the Western system, the diagnosis of cancer puts families immediately into a crisis situation, because the immediate perception is the threat of death which persists throughout the treatment and even after treatment ends. Parents describe feelings of shock, disbelief and unreality on hearing the diagnosis. The range of emotional responses differs in people where a large percentage of the populace is uneducated and illiterate and come from lower socioeconomic backgrounds. The conceptual understanding of the enormity and implications of the diagnosis are often only realised much later, once families have had a chance to consult with more knowledgeable members of their community and as the physical manifestations of the disease and treatment become more pronounced. The response, which is different or delayed can sometimes be misconstrued by health professionals as parents, 'not caring enough'.

Although both Black and White groups valued the extended family, Black people placed higher value on the interdependence, while White families valued their independence. Many Black families benefited from living within the extended family network, from which they received physical and emotional support. Research has shown that among

White cancer sufferers' incursions on autonomy and independence are most threatening. In contrast, Asian and African cultures place greater emphasis on collectivism than individualism. Chaturvedi's (1991), research highlights these differences in her study of Indian cancer patients, family members and caregivers. She found that individual functioning was rated as the least important among 10 aspects of quality of life. 58% reported that the level of individual functioning was 'not important', whereas more than 60% rated 'peace of mind', 'spiritual satisfaction', 'satisfaction with religious acts' and 'happiness with family' as very important. However, the fact that the cultural value of the family is more significant amongst some groupings does not necessarily mean that it will be mobilised or relied upon by all.

Most parents took comfort in their religion and were able to find emotional support in their spiritual beliefs especially given the life-threatening nature of the illness. Spiritual support took the form of a relationship with a cleric or a religious group who offered prayers, encouragement and support during periods of acute illness and emotional crises. This intensified relationship with God was often a plea for divine intervention for a cure in the face of feelings of uncertainty and helplessness. This sample of parents also used religion to search for the 'meaning and relevance' in the cancer diagnosis for themselves individually as parents and collectively as a family. Closely related to the search for meaning was the attempt at aetiological hypotheses testing, which parents engaged in, sometimes in an attempt to vindicate them and alleviate feelings of guilt. Hence, many responded by seeking traditional sources of healing and identified rituals that helped them make sense of the disease within the family context. This search was resolved by developing existential meaning. Spilka and Hartman (2000), aptly summarise the purpose that religion served in this study in the following terms: "religion offers to those who suffer: (a) meanings that convey hope and the potential of success; (b) increased power to counter the helplessness that accompanies despair, pain and anguish; and (c) aid from others".

While research outputs on the influence of ethnicity on cancer has been informative at the level of psychosocial care, it has not been as efficient in developing predictive models, and sometimes leads to simplistic, misleading and inappropriate conclusions.

Meyerowitz, Richardson, Hudson and Leedham (1998), suggests that the study of culture and behaviour may have greater explanatory value and greater construct validity than potentially unreliable measures of racial or ethnic categorisations. This is an ideal that can only be achieved in South Africa when the factors which have led to the huge disparities in health services and the resultant health outcomes, are eradicated.

Current inequalities in health continue to reflect historical societal imbalances. Since the advent of a democratic political order in 1994 there has been political interventions designed to change the country's social structure and foster a more egalitarian society. A decade on, social inequalities and socioeconomic differences in society generally and health in particular are still stark. Those popularly referred to, now, in a somewhat sanitised way as 'the previously disadvantaged' are no longer victims of legislated discrimination. They continue to be victims, however, of a lack of economic self-determination. For political self-determination, if it is to be meaningful and real, must go hand in hand with economic self-determination. The majority of this country's populace continue to be victims of high unemployment, a lack of tangible opportunities due in no small part to poor or no formal education and a disrupted family composition due in the main to the migrant labour system and the legacy of the Group Areas Act. In South Africa racial categorisation and the corresponding stigma or privilege which attached to it has dominated the very core of our nation's existence for centuries, impacting as it did in a direct and substantial way on every aspect of a person's being. It would be wishful thinking to believe that the eradication of institutionalised racism could simultaneously eradicate all of the attendant social ills. The role of ethnicity is thus best understood by considering the mediating variables such as the socio-economic indicators, which influence access to health care and attitudinal indicators that may have influenced the willingness to obtain care.

Psychosocial care is often not provided on a holistic and integrated basis. Instead, patients and their families tend to be conceptualised and treated without attending to their enmeshment in the broader context of caregivers, family and community. Much of the psychosocial care within the paediatric cancer context is still firmly embedded in the

tertiary health care system which is very authoritarian and prescriptive and thus not entirely suited to dealing with the diversity of the South African populace. Traditionally, 'distressed people' are referred to a social worker by an authoritative figure (eg. a doctor). While a medically orientated system of care, based on such referral paths has proven successful in first world countries, such authoritarian systems are inappropriate and archaic for dealing with psychosocial issues in South Africa especially when regard is had to the numerous alternative healing options that are available. Psychosocial issues are not necessarily medical issues hence the traditional medical care system is not capable of servicing all sectors of this country's population equally.

Traditional health care approaches often alienate those from amongst us who are socio-economically disadvantaged. Although the utilisation of psychosocial services was low, the possibility exists that if those services were available within the community context, it would be utilised. The ideal psychosocial care network should therefore be culturally sensitive, non prescriptive and equally accessible to all strata of the population. More emphasis should be placed on primary care and community networking as an effective way of reaching the increasing numbers of families confronting childhood cancer and other chronic illnesses. Psychosocial care services can also be developed in accordance with research evidence from South Africa, which will highlight how our present knowledge can be used in clinical practice to improve the quality of life for children surviving cancer and their families. Psychological *sequelae* can be reduced or prevented by the provision of appropriate accessible services.

Overall, it appeared that South African parents and children coped well with the cancer experience. How should such positive results be interpreted when the literature and research base present contradictory findings? Several explanations can be posited:

- Such differences could be attributed to methodological and sampling differences adopted in various studies and the difficulty in making generalisations from this exploratory study.
- Alternatively, positive coping could be conceptualised as 'denial', Chesler and Barbarin (1987), suggest that by utilising denial, parents avoid over-attentiveness

to the illness and in this way reduce its impact on their lives, they thus permit themselves to deal with other family issues and normalise the home environment.

- Positive coping was a façade as parents and children exaggerated their competence to create the impression of 'being in control' in an effort to remain optimistic or to avoid the pity of others and the stigma of being weak.
- The final option is to accept that families are resilient and have an amazing capacity to be temporarily destabilised initially by the diagnosis and thereafter incorporate and deal with the illness as part of their life cycle.

All of these hypotheses are viable and not necessarily exclusive of one another. However, after spending many months gathering data and listening to first hand accounts of these families, the theory of resiliency does appear seductive.

7.2 RECOMMENDATIONS

Progress in medical therapy has undoubtedly changed the psychological predicament from adapting to the imminence of death to coping with survival. Van Dongen-Melman (2000) contends that the understanding that disease-free survival is not synonymous with cure has led to a new conceptualisation of cure, which reflects the recognition that successful treatment must extend beyond biological care to the quality of survival. Hence, it is not enough to study children and their families during the first five years of their illness only, but also to examine the late consequences of cancer and plan psychosocial aftercare with this in mind. An integrated, comprehensive and well-organised psychosocial care network dealing with all phases of the illness and treatment, involving patient, family and even the wider community is required.

The question is whether there is a need for psychosocial care in South Africa especially in the light of the discussion, which highlighted the resilience of children and their families in the absence of a well organised psychosocial care system? The sheer complexity, seriousness and long term nature of psychosocial problems indicates a dire need for psychologically based intervention not only for the children diagnosed with cancer but also for their families who face many challenges. Presently, most

psychological services are available privately or within the psychiatric clinic/unit context. This is definitely far from ideal. There is a lack of intervention programmes addressing the illness and termination phases of the cancer treatment. It becomes imperative to analyse some of the difficulties that potential subscribers to health care services experience that possibly deters them from using psychosocial services.

A systems/social ecological approach necessitates involvement and intervention at multiple layers: patient, parents, siblings, social network, educational system and at a policy level. Intervention will only be successful if there is adequate knowledge of the various settings and a realistic appraisal of the most appropriate form of intervention for each context. More attention is needed on how ethnic values and beliefs may effect family interactions with health care and educational systems. Given the wide array of disease and family variables, which warrant inclusion, creative inter-institutional research using many different forms of methodology (eg. longitudinal studies, ethnographic and observational methodologies) and practical endeavours are required to enhance our knowledge base.

In theory and practice the psychosocial typology of illness is seen as an adjunct rather than an integral part of the disease classification. Hence, disease classification is based predominantly on biological criteria that are clustered in such a way as to establish medical diagnosis and treatment plans. Psychosocial practitioners thus only become involved in the care of individuals or families coping with the illness at different points in the illness trajectory (eg. during periods of crisis) rather than following patients and their families through the complete life history of the disease. Rolland (1999) argues that we need a schema to conceptualise chronic diseases that remains relevant to both the psychosocial and biological worlds and provides a common language that transforms our usual medical terminology.

South Africa is a third world country with low levels of resources (multidisciplinary staff, health care facilities) in the health care system to deal effectively with the demands of childhood cancer, thus family needs will inevitably exceed staff availability. Drell (2003),

articulates some of the issues that the medical team face on a regular basis: multiple losses and their impact, the coexistence of mental disorders which sometimes complicates the relationship and treatment of children with cancer, the problem of boundaries, dealing with religious and cultural biases especially when it interferes with treatment schedules and protocols and stressors in their personal lives (eg. illness, divorce, death, family life cycle events, etc.). These issues present human dilemmas and complicate the work of the team. Often the focus is on the patient and family with insufficient attention given to the health care team and hospital. A highly neglected area in health care are the emotional needs of staff, hence more attention needs to be given to the emotional toll this type of work takes on health care personnel. Regular debriefing and support group sessions would serve a protective function and reduce fatigue and burnout.

7.3 LIMITATIONS

This research represents a descriptive examination of the psychosocial implications of childhood cancer for children and their families. The findings of this study explain the types of communication concerning the cancer experience, the emotional response which accompanies the diagnosis and treatment, and the coping resources utilised. This study should thus be recognised as baseline information and interpreted in the light of a number of limitations.

The first major limitation is that this study relied on a single assessment of participating children and their parents. According to Sawyer et al. (1997), the prevalence of problems experienced by children with cancer varies at different points in time and with the age of the sufferer. This study was unable to assess the changes, which may have occurred over a period of time, hence the need for prospective studies. In addition, the statistical analyses did not test specific hypotheses; hence not many relationships or causal contentions can be ventured. Due mainly to economic reasons, fathers did not accompany children to treatment; it would thus be useful to incorporate them into future studies, in order to assess their response to the illness. The assessment of sibling's emotional responses and coping mechanisms could also enrich our understanding of the impact of

disease on them. As well as if appropriate support is to be provided to them, it is important to understand their own views of their experiences and the resources they rely upon.

This study relied heavily on standardised measures to assess psychological adjustment and coping strategies. Quantitative research methods often fail to capture how people make sense of and find meaning in the cancer experience. Using qualitative methods and assessing the narratives would provide additional meaningful insights about the cancer experience for both children and parents.

Cancer is a generic term representing a number of malignancies, each with its own physical presentation, course and treatment. Assuming that all children diagnosed with cancer will share a common experience may be inappropriate. Although many dynamics are the same, an in depth comparative analysis could help elucidate differences between diagnostic types.

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APPENDICES

Appendix 1

Communication variables

1.1 Responses in content interview

Topic	Percentage %
<i>Sick child's primary social support and information source within the family</i>	
Mother	36%
Father	7%
Both parents	10%
Siblings	6%
Other	11%
No one	30%
<i>Communication about the disease with others</i>	
Friends/classmates	4%
Fellow patients	90%
Teachers	27%
Relatives outside the immediate family	35%
Others	3%
<i>Frequency with which parent initiates discussion about illness with sick child</i>	
As often as the child wants	24%
As often as parent wants	22%
As the need arises (seldomly)	30%
Not at all	24%
<i>Which parent answers questions asked by the sick child</i>	
Mother	58%
Father	8%
Both parents	18%
No one	16%
<i>Communication about disease with well siblings initiated by Oncology staff</i>	
Yes	88%
No	12%
<i>Do you find it helpful talking to other parents?</i>	
Yes	64%
No	36%

Do you think it would be useful to participate in a support group?

Yes	73%
No	27%

Traditional healing

Healing sought	31%
Prayer but not traditional healing	60%
No prayer or healing sought	9%

Use of sedatives by parents

Yes	49%
No	51%

Parental ill-health for which medical attention was sought

Received medical attention frequently	14%
Received medical attention during stressful times only	24%
No need for medical services	63%

Positive experiences with regards to the disease

Absence from school	20%
Watching a lot of TV	50%
Receiving gifts	60%
Getting a lot of attention	72%
Becoming mature	12%
Nothing positive	31%

Negative experiences with regards to the disease

Hospitalisation	87%
Chemotherapy and other invasive medical procedures	70%
Pain	65%
Feeling sick	69%
Loosing hair and other bodily changes	35%
Missing friends	53%
Teasing	28%
Not playing sport	42%
Fear of death	4%
Absence from school	23%

How frequently do you talk about your child's illness to your partner?

Frequently	39%
Seldomly	25%
Not at all	13%
N/A	23%

<i>Who initiates the conversation?</i>	
Husband	15%
Wife	48%
Neither	13%
N/A	24%

Appendix 2
Research Questionnaire

RESEARCH QUESTIONNAIRE

**THE PSYCHOSOCIAL EFFECTS OF CANCER ON CHILDREN
AND THEIR FAMILIES**

**VINITHA JITHOO
DEPARTMENT OF BEHAVIOURAL MEDICINE
NELSON MANDELA SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES
UNIVERSITY OF KWA-ZULU NATAL
DURBAN**

CLINICAL BIOGRAPHICAL DATA

Date

Usuku _____

Patient Details

Imininingwane Ngesiguli _____

Name

Igama _____

Date of Birth

Usuku lokuzalwa _____

Age

Ubudala _____

Sex

Ubulili _____

School

Ufundekuphi _____

Grade

Ibanga lemfudo _____

Birth Rank

Isifo esikugulisayo _____

Nature of Diagnosis

Ubude besikhathi ugulile _____

Duration of illness

Indlela oloshwa ngayo njengamanje _____

Treatment received currently

Uyisiguli esilashelwa ngaphakathi

Inpatient

Kusiphi isibhedlela _____

Which hospital

Igama lomtholampilo _____

Outpatient

Uyisiguli esilashelwa ngaphandle _____

Name of hospital/clinic/doctor

Igama lomtholampilo/isibhedlela/ikliniki/uDokotela _____

FAMILY DETAILS
IMINININGWANA YOMNDENI

Name Igama	Age Ubudala	Gender Ubulili
Mother Umama		
Father Ubaba		
Other children Abanye abantwana emndenini		
1.		
2.		
3.		
4.		
5.		

FAMILY SYSTEM
UHLOBO LOMNDENI

Two parent family
Abazali ababili ababambisene
Single parent family
Umzali oyedwa/ozimele
Extended family
Umndeni oxhumene

Educational level of parents
Imininingwane ngemfundo yabazali

Mother
Umama _____

Father
Ubaba _____

Socio-economic status of family
Izinga lomndeni ngeqophelo lenhlalo-mnotho

High
Liphezulu /liphakeme
Middle
Liphakathi
Lower
Liphansi

Religious and cultural background
Inkolo namasiko

Ethnic background
Ubuzwe _____

Religious upbringing
Inkonzo yokukhuliswa _____

Present church, mosque, temple, synagogue etc. attendance
Ukhonza kuliphi ihlelo: nakusiphi isigaba _____

INTERVIEW WITH CHILDREN
INKULUMO MBUZO YABANTWANA

A. KNOWLEDGE OF DISEASE
UBWAZI NGESIFO

1. What is/was wrong with you that made it necessary to be seen by a doctor?
Yini ekuphethayo noma eyayikuphethe eyabayimbangela yokubonana
noDokotela? _____

2. What else do you know about the disease?
Yini enye oyaziyo ngalesisifo? _____

3. Do you still have the disease or are you better?
Usaguliswa yilesifo noma izizwa usungcono _____

4. Do you still receive treatment?
Uselashwa namanje? _____

**B. SOURCES OF INFORMATION ABOUT THE DISEASE
IMITHOMBO YOLWAZI NGESIFO**

1. Who told you that you were suffering from this illness?
ubani owakutshela ukuthi uguliswa yilesifo?

Mother
Umama
Father
Ubaba
Doctor
UDokotela / Inyanga
Nurse
Umhlangikazi
Other people
Kungaba ubani futhi

Who? _____

2. What did they tell you?
Yini abakutshela yona? _____

3. When did they tell you?
Watshelwa nini? _____

4. Who have you asked to know more about the disease?
Ubani omunye omcele ukuba akutshela kabanzi ngalesisifo _____

5. What did they tell you?
Ukutshela ukuthini ngalesisifo? _____

**C. COMMUNICATION ABOUT DISEASE WITH PARENTS
INGXOXO NABAZALI NGESIFO**

1. Who in your family do you talk to most about your illness?
Ubani emndenini oxoxa naye kabanzi ngalesisifo sakho? _____

2. What did your parents say to you about your illness?
Bathini abazali bakho ngalesisifo esikugulisayo? _____

3. Do your parents often talk to you about your illness?
Bavamisile yini abazali bakho ukukuxoxisa ngokugula kwakho?

**D. COMMUNICATION ABOUT DISEASE WITH OTHERS
UYAXOXA YINI NABANYE-NJE NGALESISIFO**

1. Who have you spoken to outside your family about your disease?
Ubane ongekho emndenini oke uxoxe naye ngalokugula?

Friends
Abangane
Classmates
Omunye funda naye
Class teacher
Umfundisi – nsapho
Other patients
Omunye weziguli
Others
Ubani –nje omunyeke

**E. POSITIVE AND NEGATIVE EXPERIENCES IN REGARD TO THE
DISEASE**

1. What is the worst thing/s about having this disease?
Yini embi kakhulu noma zintozini ezimbi khahulu ekugulisweni yilesisifo?

2. What are some of the advantages of having the disease?
Yini oyibona nokho ingeyimbi kangako ekubeni nalesisifo?

**INTERVIEW WITH PARENTS
INKULUMO MBUZO MABAZALI**

A. COMMUNICATION ABOUT DISEASE WITH CHILD

1. What have you told your child about his/her illness?
Yini oyitshela umntwana wakho ngalesisifo esingulisayo?

2. What information have you not given your child concerning the diagnosis and prognosis?

Yini oyi godlile wangamtshela yona umntwana wakho ngalesisifo nomphumela waso?

3. How often do you talk to your child about his/her illness?
Kuvamise kangakanani ukuxoxisana kwakho nomntwana wakho ngesifo esingulisayo?

4. Which parent answers questions about the illness?
Njengabazali imuphi kunina ophendula imibuzo ngalesisifo?

5. Do you express grief, or worry in the presence of the child?
Kuyenzeka yini uveze obala ubuhlungu nokuzwela phambi komntwana?

6. Do you enquire about your child's worries or grief?
Uyabuza yini ngokukhathazeka nokuzwela komntwana?

7. Do you talk to your child about other patients who have died?
Kuyenzeka yini uxoxe nomntwana ngabanye abagula njengaye abashonayo?

**B. COMMUNICATION ABOUT DISEASE TO SIBLINGS
INGXOXO NABANTWANA BAKUBO KWESIGULI**

1. Have you discussed the illness with your other children?
Anike nixoxe ngalokugula nabanye abantwana bako / benu?

2. What information have you given them?
Ubanike lwazi luni?

3. What questions have they asked you?
Imiphi imibuzo abakubuza yona?

C. COMMUNICATION ABOUT DISEASE WITH PARTNER
INGXOXO NGALESIFO NOBAMBISENE NAYE

1. How often do you talk about your child's illness to your partner?
Nivamise kangakanani ukuxoxa nawakwakho ngesifo esigulisa umntanakho/wenu?

2. Who initiates the conversation?
Ubani oye aqalize ngenkulumo phakathi kwenu?

- D. Do you find it necessary/helpful to talk to other parents with sick children?
Kunosizo noma kudingekile yini ngokubona kwenu ukuxoxa nabanye abazali abanabantwana abaguliswa yilesisifo?

- E. Do you participate in a parent support group?
Nina-ke niyiyona yini ingxenye yombutho wabazali abaxhasanayo?

- F. Do you think it is useful to have a parent support group?
Nicabanga ukuthi kunosizo ukubanombutho wabazali abaxhasanayo?

- G. Has the doctor spoken to your sick child and / or other children about the disease?
UDokotela ukewaxoxo yini nomntanakho noma nabanye abantwana ngalesisifo?

H. What type of feelings have you experienced when talking about cancer to your children?

Uzizwa ubanjani ngokwemizwa uma uxoxa ngomdluza nabantabakho?

I. Have you withheld any information about the illness to your sick child or other children?

Kukhona yini okugodlile wangamtshela umtonokho ogulayo – noma abantakho abanye ngalesisifo.

J. Have you sought information about your child's diseases from other sources? Please explain.

Ukewazama yini ukuthola ulwazi kabanzi ngalesisifo esigulisa umntanakho kwezinye izizinda? Sicela uchaze

K. Have you sought religious / traditional healing?

Uke wazama yini ukuthola usizo kubathandazi noma izinyanga ngamakhambi eSintu?

If yes, please state where, when and what.

Uma kunjalo isho ukuthi: Kuphi, nini, and kwakuyini?

L. BEHAVIOURAL DIFFICULTIES

UBUNZIMA OBUHAMBELANA NALESISIFO

1. Does your child experience any difficulty with the following:
Umntwana ubhekene nobunzima kokunye kok ulandelayo:

YES NO

a) sleeping problems
ulala kanzima

☐ ☐

b) eating problems
udla kanzima

☐ ☐

c) bed wetting
uyaphunyuka uma elele

☐ ☐

d) problems at school
ubunzima esikoleni

☐ ☐

e) socializing with friends
ukungcebeleleka nabangane

☐ ☐

f) playing sport
ukudlala emidlalweni

☐ ☐

- g) severe pain ☐ ☐
 usebenzisa imithi uma efuna ubuthongo noma ukudambisa
 izinhlungu
- h) have you used sleeping pills or sedatives during your child's ☐ ☐
 illness?
 wena-ke mzali ulala ngokusebenzisa am aphilisi aletha
 ubuthonga njengoba umntwana egula nje?

How often?
 Kangaki?

- M. How often have you seen your doctor during the past 3 months for your own
 complaints?
 Ezinyageni ezintathu ezidlule umbone kangaki uDokotela maqondana
 nokungaphatheki
 kahle kwakho? _____