

**UNIVERSITY OF KWAZULU-NATAL**

**UNDERSTANDING HIV/AIDS EFFECTS  
THROUGH SYSTEMS PRINCIPLES:  
A CASE STUDY OF HOME-BASED CARE GIVING IN  
BHAMBAYI**

**By**

**Thenjiwe Meyiwa**

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**By  
Thenjiwe Meyiwa  
901350570**

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Organisational and Management Systems.

**Leadership Centre  
Faculty of Management Studies**

**Supervisor: Professor Suzanne Leclerc-Madlala**

**2009**

# DECLARATION

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I .....declare that

- (i) The research reported in this dissertation, except where otherwise indicated, is my original research.
- (ii) This dissertation has not been submitted for any degree or examination at any other university.
- (iii) This dissertation does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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Name: Thenjiwe Meyiwa

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## ABSTRACT

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This dissertation, employing an array of theoretical approaches under the rubric of *Systems Thinking*, explores the reality and experiences of family members that mainly provide care at home for their loved ones who live with or are directly affected by HIV & AIDS. Employing a multidisciplinary approach, the dissertation demonstrates how *Systems Thinking*, feminist and indigenous knowledge principles can be employed for a better understanding of the contemporary construction of family and experiences of caregivers in an HIV & AIDS context. The discussion of the dissertation is based on data analysed following in-depth interviews with fifteen caregivers of the Bhambayi community. The findings of the study reflect a significant change in the definition and practice of parenting. It was found that HIV & AIDS forces a re-definition of the concept and practice of parenting beyond the traditional boundaries of age, sex and gender. Aligned with this main finding was that parenting practices and coping strategies are largely influenced by a strong commitment to the well-being of the children as well as societal constructs. The thesis of this dissertation is that the HIV & AIDS context and associated gender and cultural stereotypes are principally responsible for a significant shift in the understanding of the concept and practice of parenting within an African context. The study thus submits that a *Systems Thinking* approach ought to be used by interventionists to better understand and thus contribute towards improving the lives of families or communities in similar circumstance as that of the Bhambayi families.

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# **CHAPTER ONE**

## **Introduction and context of the study**

### **1.1. Introduction**

The discussion of this dissertation rests on the assertion and recognition that home-based care is a socially constructed and gendered phenomenon that has problems different from other forms of health care giving. In turn, individuals involved in home-based care carry out their daily duties based on life experiences informed by unique socio-cultural contexts. For the past five years, I have closely interacted with families that are involved in home care, specifically caring for either one or more of the following: children orphaned by AIDS, children infected by HIV & AIDS, or adults infected by HIV & AIDS. Over the years the interaction has provided me with a basis for the development of insights into a number of problems and needs of the families I studied. I hold that the choices they make and activities they engage in are influenced by a list of socially-constructed expectations and misconceptions around HIV & AIDS, some of which have a negative bearing on their duties and general well-being.

According to van de Wouwer (2005:149) the impact of a people's values on HIV & AIDS cannot be underrated. He contends that, at a community level, commonly-held stereotypes reveal people's perceptions, attitudes and behaviour towards AIDS. (For a further discussion on stereotypes, see Chapter four). If they were to have adequate general well-being, families and individuals infected and affected by HIV & AIDS would enjoy good health; have good interpersonal relations within and outside the family, as well as make a much more meaningful contribution at personal, family as well as at a societal level.

In the discussion of the dissertation, I refer to this ideal kind of well-being as 'holistic well-being'. The term is not used in the manner in which psychologists and/or health practitioners use it. In the context of this study, it means the maximum level of feeling healthy, i.e. rather than focusing on illness or specific parts of the body, this holistic approach to one's wellness considers the whole person and how he or she interacts with his or her environment. It emphasizes a balanced connection of mind, body, values, expectation and spirit. If they attain holistic well-being, the care-givers would be able to enhance their efficacy in care-giving and in turn maximise chances of prolonging theirs and the life span of people under their care. In

reality, however, home care-giving individuals and families confront a number of problems with complex gender and socio-cultural dynamics.

This dissertation is thus an attempt to explore the interweaving as well as complex<sup>1</sup> character of gender, societal and cultural beliefs held by the Bhambayi community. This is with the intention to understand how these variables impinge on the holistic well-being of the status of people within families that provide care in an HIV & AIDS context. Taking these facets into consideration the discussion of this dissertation demonstrates how *Systems Thinking*, and feminist and indigenous knowledge principles can be employed for a better understanding of the contemporary construction of femininity and masculinity in the lives of caregivers in an HIV & AIDS context. I adopt a multidisciplinary research approach in an attempt to understand and explain the complex character of care giving in a HIV & AIDS context. This attempt is made drawing from and contributing to the bodies of knowledge in gender-based research, soft systems methodology, feminist studies, family studies, and indigenous knowledge approaches.

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<sup>1</sup> The complexities include changing gendered parental roles, contrasting feminine vs. masculine identities, development of unique identity, socio-cultural construction of gender roles & relations within and outside the family, strategies employed by caregivers to cope with strain put on their families due to misconceptions around HIV & AIDS.

Bearing the above discussion in mind and further contextualising the study, the discussion of this chapter is on the:

1. Geographical location and economic context;
2. Context and background of the study;
3. Statement of the problem;
4. Research objectives; and
5. Key questions the study poses.

## **1.2 Bhambayi's geographical location and socio-economic context**

The area of study is referred to as Bhambayi as it is commonly known by its residents and many other Durban-based people. In the last three decades it has grown around the Phoenix Settlement as an informal settlement. Citing Fischer (1893), Benjamin (2005:39) notes that the area is also known as Phoenix Settlement, the place where the late Mahatma Gandhi, one of the foremost Indian spiritual and political leaders of the 1900s, lived and worked. The historical Gandhi settlement is found in this area and, during the struggle against apartheid served as a place of refuge and was used for political workshops and seminars. A number of scholars who write about Bhambayi (e.g. Johnson, 1994 and Benjamin, 2005) point out its significance as an area with a rich political and historical heritage. It stands

to reason then that the area is presently a South African Heritage site. Besides its connection to Gandhi, Johnson lists key South African activists who spent weekends there and during which they instituted a trade union movement, i.e. Rick Turner and Steve Biko.

Bhambayi falls within the eThekweni metropolitan area and has come to be known by the municipality as part of the INK (Inanda, Ntuzuma and KwaMashu) area. It is located about 30-40 kilometres north of the Durban city centre, in the district of Inanda in the Province of KwaZulu-Natal. Inanda 'comprises a mix of formal residential townships and informal settlements which are home to approximately 510 000 residents' (EThekweni Municipality Geographical Information Systems' website). According to the website Bhambayi is the second largest agglomeration of poor neighbourhoods in South Africa with many of its households experiencing high levels of unemployment,<sup>2</sup> social dislocation, poverty and crime, exacerbated by inadequate physical infrastructure and severe degradation. The Bhambayi population demographics have rapidly changed over the years 'as movement of people from the rural areas to the urban areas became commonplace' (Benjamin, 2005:39). In its earlier years of development some South African Indians lived in the area.

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<sup>2</sup> According to the St Martin's Church's outreach programme more than 50% of the residents are out of employment ([www.stmartinschurch.co.za](http://www.stmartinschurch.co.za)). The church is one of the organisations that help the most vulnerable individuals (destitute and orphaned) of Bhambayi – with food parcels, clothing and schooling needs.

Currently the Bhambayi housing is mainly of the informal type, that is, of poor construction with limited living space (see figures 1.1 & 1.2 below). It is less than 10 minutes drive from an affluent area, Durban North. Most of the Bhambayi houses are made from wattle and daub, with no water or electricity. Homes are hot in summer and cold in winter and there is poor ventilation whilst dampness is cited by Benjamin (2005:29), a health practitioner, as one of the serious causes for concern which negatively impacts on the health and well-being of its inhabitants who live badly built houses. Sanitation is primitive (the pit privy system) which is poorly constructed, in most instances, 'with as many as ten households sharing one toilet' Benjamin (2005: 12).



Fig. 1.1 & 1.2 Bhambayi, depicting kinds of households in the area



(Fig. 1.1. & 1.2. Bhambayi informal dwellings looking northwards. Picture by the researcher. July, 2008)

### **1.3 Context and background to the study**

HIV & AIDS is one of the biggest health challenges that the nations of the world have ever had to face. Global literature and statistics (UNAIDS Reports, 2006 & 2007 and Farmer, Connors & Simmons 1996:152) cite southern Africa as the worst hit region. The impact of HIV & AIDS in South Africa has become so immense that no person or sector can afford to ignore it, or employ only one kind of strategy in trying to understand or combat the disease. HIV & AIDS have major effects on the lives of South Africans, especially families. Children become orphaned or are made vulnerable by the pandemic on a daily basis. Consequently, numerous HIV & AIDS statistics and literature concern the children. For instance, UNAIDS, 2004 estimates that 1.1 million children under the age of 18 years have lost one or both parents to AIDS and assert that it will increase to approximately 3 million orphans by 2015. Given the devastating effects of the pandemic it is essential to understand it from as many bodies of knowledge as possible. Of note, however, is the fact that there is little literature on understanding the impact of the pandemic on the lives of families from a soft *Systems Thinking* point of view. Existing literature deals mostly with the impact of the HIV & AIDS status of adults on their children from clinical, cultural and sociological approaches. There is therefore a distinct gap in the literature on the soft systems approach to understanding and explaining how HIV & AIDS impacts on families. It is therefore crucial to have studies that seek to understand

and present data from soft systems methodology. I contend that this study is an effort towards filling the identified scholarly fissure.

Research, literature and social service providers for families mostly concentrate on adults living with the HIV virus or on AIDS-orphaned children. It is of note that although there is a growing literature<sup>3</sup> on other family experiences, there has been minimal reporting on care giving and parenting children orphaned by the disease. Besides, only limited literature is available on the practices and experiences of mothering within this context – one of the aspects on which this research sought to concentrate.

Elizabeth Thompson's (2000) work discusses the experiences and responses of mothers in AIDS affected families. Its focus is, however, on adult children, and the paper is drawn from a US based study. Another work on HIV & AIDS parenting is that of Stajduhar (1998). It refers to mothers' experiences in a study on family care-giving situations. A masters degree study by Wong-Wylie (1997) is worth noting as a significant contribution towards a body of literature on how families (beyond the patients and those who mainly take care of them) are affected by HIV & AIDS.

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<sup>3</sup> This dissertation includes a discussion on the literature of the themes and issues related to the research problem. It is, therefore, purposeful that I do not exclusively concentrate on reviewing literature.

This dissertation largely emanates from a four-year-long study, (2004-2007) that focused on the aftermaths of HIV & AIDS in a community of the region of KwaZulu-Natal, South Africa. The region is geographically positioned north of Durban, one of the main economic centres of the country. The location of the study is Inanda, a Bhambayi shack-dwelling and informal settlement (see figures 1.1 and 1.2 above). The aim of the four-year study was to examine and record ways in which households cope under HIV & AIDS circumstances. In 2009 the area was again visited to validate the data I had earlier collected. Out of this study, I observed that HIV & AIDS has had numerous effects on affected families that in turn lead to forced changes in the manner in which families have traditionally defined themselves and related with other people.

Similar studies on Bhambayi have been conducted. Of note is a study by Benjamin (2005) which makes reference to a study conducted by the ML Sultan Technikon Department of Health Care Services. The latter study provides statistics indicating that 28.5% of the Bhambayi sample population comprise of HIV & AIDS sufferers (cited by Benjamin, 2005:2). According to Benjamin (*ibid.*), the estimation was determined by applying WHO (2000) guiding principles for making a diagnosis when HIV testing is not available. Benjamin says that HIV infected people identified in the survey, were found to be in a state of neglect, often without food and very ill, making it

physically impossible to access the local health facilities for treatment. Some, Benjamin asserts, were dependant on the charity of their neighbours for essential basic needs such as food. The survey further pointed out that other related health problems, for example that 37.1% of the sample was known to be suffering from Tuberculosis (TB), of which 59% were not on treatment (Benjamin, 2005:8).

#### **1.4 Problem statement**

Anyone infected by HIV and who dies from AIDS has family members, relatives, guardians, friends and caregivers. What is a challenge is not only the life of the infected individual, but an entire circle of people is also profoundly affected. They, like the main victim, also need care, support and a sympathetic audience able to listen to their tales of woe and despair (Macklin, 1989). The family members' perspectives are necessary to get a holistic picture of the impact and effect of AIDS (Tiblier, Walker & Rolland 1989: 78; Wong-Wylie, 1997: 69 and Thompson, 2000:21).

UNAIDS Reports (2003-2006) cite AIDS as a disease that has surpassed malaria as the leading cause of death in Africa. These reports reflect a significant need of improved support for family care giving and in particular,

women involved with HIV & AIDS. Prior to these reports, several scholars (Richardson, 1994:121; Gupta & Weiss, 1996:60; Tallis (a), 1997:10 and Tallis, 1998:2) had expressed concern that HIV & AIDS is a crisis for women, given the greater vulnerability of women to HIV infection even within family care-giving environments.

Studies in home-based care giving (Stajduhar, 1998:18; Whiteside and Sunter, 2000:133; Songwathana, 2001: 265; Uys, 2002:77 and Akintola, 2004: 11) note that experiences of people involved in care giving portray HIV & AIDS as an intense, emotional experience filled with pride and enrichment, but equally imbued with anger and disillusionment. It is partially to this end that the United Nations developed a Task Force to study the intersections of HIV, care and gender. Two of the six issues that the Task Force's work identified were on care giving:

1. The role of women and girls in caring for those infected and affected by HIV & AIDS; and
2. Access to HIV & AIDS care and treatment for women and girls.

The other four were:

3. Prevention of HIV & AIDS among young women and girls
4. Girls' education

5. Violence against women and girls
6. Property & inheritance rights of women and girls

### **1.5 Research objectives and key questions addressed in the research**

The primary objective of this study is to explore and explain the manner in which *Systems Thinking* methodology can be applied in an attempt to understand the impact of HIV & AIDS on families and individuals that take care of people affected by the disease. This objective has subsidiary objectives and questions; i.e.

#### **1.5.1 Subsidiary objectives**

- To identify issues that may be interconnected and interdependent – that affect families caring for people with HIV & AIDS;
- To examine the impact that each issue has on another, i.e. the causal links between issues; and
- To examine the construction and meaning of the terms 'family' and 'mother'.

### **1.5.2 Questions**

- What components within interactions with family and community members affect the holistic well-being of persons living with HIV & AIDS?
- From the perspectives of the affected families, what is 'family'?
- What coping and survival strategies do caregivers use in their practice?

### **1.6 Key concepts used in the study**

#### *System:*

A web-based systems' management resource defines a system as an organised collection of parts (or subsystems) that are integrated to accomplish an overall goal. It further notes, 'The system has various inputs, which go through certain processes to produce certain outputs, which together, accomplish the overall desired goal for the system' (<http://www.managementhelp.org/systems/systems.htm>). A system should therefore be understood to have various inputs, which together, ideally, should accomplish the overall desired goal for a system. In the context of this study, the family is a sub-system of a larger system, the community.



### *Systems Thinking:*

One of the recent leadership and management advances in how people understand and guide change in organizations is through systems theory and *Systems Thinking*. *Systems Thinking* came about as a reaction to reductionism, when Von Bertalanffy (1968:11) called for an interdisciplinary approach to studying problem situations.

### *Systems approach:*

The term refers to methodologies for problem solving and design related to Systems Thinking.

### *Soft systems approach:*

Different views about a system have subsequently emerged, namely hard<sup>4</sup> systems, soft systems, critical<sup>5</sup> systems and, recently, disclosive<sup>6</sup> Systems Thinking. *Soft Systems Thinking* employs a more holistic approach to systems properties as it asserts that a system has relationships between parts and wholes (Beer, 1985:27 and Coetzee, Graaf, Hendricks and Wood

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<sup>4</sup> A term used by Checkland (1981) as an alternative to soft systems – whereby social systems are treated like scientific problems.

<sup>5</sup> Critical systems thinkers assert that as the world is not fundamentally harmonious, one must think of its contradictions in order to understand, explain and make necessary changes

<sup>6</sup> Introduced by Strijbos (2000) to address and explain the responsibility of people for certain developments.

(2001). In soft systems methodology, Goede (2005:3) holds that user satisfaction is more important than requirements conformation. The discussion of this dissertation uses the terms, soft systems approach, soft *Systems Thinking*, soft systems methodology and soft systems theory in one breadth and as interchangeable to mean the same thing.

#### *Gendered identity:*

Societal and personal processes involving internalisation and acting out of sex-determined standards, gender-role identities, and gender roles.

#### *Gender roles:*

Refer to behavioural patterns and sets of roles defined by society as masculine and feminine, which are culturally regarded as appropriate to males and females.

#### *Social construction:*

Is about the way social phenomena are created, institutionalised and absorbed into tradition by human beings and these traditions, in turn become part of their culture.

### *Feminism:*

This is a set of varied social beliefs, moral philosophies or a movement mainly motivated by or concerning the experiences of women, especially in terms of their social, cultural, political, market-related, and broad economic circumstances. Feminism as a social justice movement focuses on limiting or eradicating gender inequality and promoting women's rights, interests, and issues in society. Contemporary feminism also incorporates concerns about marginal groups that may not necessarily be of the female gender.

## **1.7 Structure of the dissertation**

In accordance with the key issues addressed in the study and the research questions above, the following sections constitute the structure of the dissertation.

### **Chapter 1:**

In this chapter, there is a discussion of the background to the study and context. Further, the discussion presents the research problem, research objectives, as well as key questions and issues addressed by the research. The layout of the dissertation and highlights of each chapter also form part

of this section. Lastly, there is a list and explanation of concepts that frequently appears in the discussion of the dissertation.

## **Chapter 2:**

The main theories used to explore, understand and explain the research problem are discussed in this chapter. To this end the study draws on a number of related thoughts under the rubric of *Systems Principles*. These theories are referred to as a set of theories that do not only 'speak well' to each other but best explains the Bhambayi research problem.

## **Chapter 3:**

This chapter is about the process regarding the selection of a specific research plan. It documents the methodologies to be employed, and justifies their usage. The process undertaken, ethical considerations and limitations encountered are also detailed. The study is qualitative in design with the objectives of the research achieved by employing social research practice, and action research. I explain these practices using *Systems Thinking* theory. There is also a discussion on practice adopted in data gathering and analysis.

## **Chapter 4:**

*Systems Thinking*, care giving and HIV & AIDS is the title of this chapter. The chapter contextualises all these three elements into a single discussion and does so highlighting societal constructs that negatively impact on people affected by HIV & AIDS.

## **Chapter 5:**

Chapter 5 offers data analysis and findings in a narrative format and attempts to do so within a framework that argues for the relevance and value of using *Systems Principles* as an analysis tool.

## **Chapter 6:**

This chapter focuses on the conclusion and final thoughts on the research problem. Whilst it reflects on the research problem, it offers insights into intervention and developmental strategies that could significantly improve the lives of people directly affected by HIV & AIDS.

### **1.8 Limitations of the study**

The fact that the study, and hence the dissertation, is only part of an MA degree limits its depth and analysis. The sample is small and the study does not claim to be exhaustive or representative in its intent. The discussion, though having possibilities to apply to a bigger sample with similar challenges, should not be understood to readily apply to the entire Bhambayi community, all families that are affected by HIV & AIDS or the entire Zulu-speaking people.

Though the chosen line of analysis is multidisciplinary it is not all the elements of each theory that are used. Given the limited scope of the dissertation I have opted to use only a few elements of each theory – only those that were found to be appropriate for the case study at hand.

### **1.9 Chapter summary**

The objective of this chapter has been to introduce the reader cursorily to the Bhambayi community, briefly state some of the challenges it faces and introduce key concepts that form part of the discussion of the dissertation.

## **CHAPTER TWO**

### **Theories used in the study**

#### **2.1 Introduction**

Hughes (2002: 76) submits that any text is built on some kind of theoretical or conceptual framework that may or may not be made explicit. Nevertheless, the importance or benefit of working within the confines of a theoretical framework 'places the knowledge presented in a broader epistemological and ontological field' (Hughes, 2002:38). Bertrand and Hughes (2005: 262) describe a theory as a 'set of concepts, derived from and contributing to a model, which together explain a phenomenon or practice'. This study assumes that theories do not only operate and are understood as the origin of ideas; they also help to facilitate the 'connection of ideas', as Albrow (1999: 41) notes. This connection of ideas concerns itself with facilitating and consolidating the link between a researcher's concerns, aims and objectives with particular aspects of the tangible realities of their studies.

The purpose of a theory, therefore, is to carry forward the various structured ideas within the Bhambayi research whilst at the same time work as a point of origin for the ideas and views contained in the discussion of the dissertation. This section therefore captures the theories that underpin my investigation of the lives, experiences and coping strategies of selected Bhambayi families directly affected by HIV & AIDS. It is significant in clarifying arguments discussed in the dissertation as well as analysis of the research participants' stories.

This chapter thus presents a discussion on the philosophies I use to contextualise and explore the research problem (HIV & AIDS and care giving) in an attempt to offer an explanation of the problem from a soft systems approach. The soft systems approach takes an upper hand in understanding the research problem. Given the socio-cultural characteristic of the problem, however, it is imperative to draw from socio-cultural theories that I consider relevant to the case study, i.e. *Systems Thinking*, grounded theory, feminist theory, indigenous knowledge systems and social constructionist theory.



## 2.2 Systems Thinking

The purpose of this section is to advance the discussion on systems and *Systems Thinking*. A system, defined as a set of interrelated elements by Ackoff (1971:38), is usually made up of many smaller systems, or sub-systems. A system is a term that is often used in corporate or formally-structured organisations. This study, nevertheless, adopts this definition and applies it to the case study at hand; a community of families of Bhambayi are also deemed to be a system. This dissertation submits that the studied community could be regarded as a system that is made up of a number of structures; i.e. services, groups, families, individuals etc. It further subscribes to the idea that if one part of the system is changed, the nature of the overall system is often changed (Checkland and Scholes, 1999: 123); a phenomenon that presents itself in the analysis of the case study of this dissertation. Checkland and Scholes maintain that a system must change or survive changes in the environment in order to be able to tackle complex problems.

*Systems Thinking*<sup>7</sup> emerged as a reaction to reductionism, hence the need to give a brief discussion of the traditional scientific approach. Checkland

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<sup>7</sup> The *Systems Thinking* approach was proposed as a method to overcome the shortcomings of traditional scientific approaches.

(1981) discusses in detail the manner and reasons why systems approach came about. Plato and Aristotle are world renowned for the development of the art of rational thinking. They maintained that experience is gained through deliberate, designed and repeated experiments. The experiments are understood to be designed to allow the scientist to formulate laws that govern the regularities of the universe, which are mathematical in character. Three key aspects of the scientific method are reductionism, repeatability and refutation. In practice, this means that an experiment can be seen as a reduction of the real world, a reduction for a specific purpose, and it can only be valid when it is repeatable (see figure 2.1 below).

Critiquing this kind of explaining the universe and its practices, Checkland (in Goede, 2005:71) argues that 'by means of the reduction of the real world into an experiment, the researcher aims to control the investigation completely, so that the changes that occur, are the result of his actions, rather than the result of a complex interaction of which he is unaware'. In short, reductionism propagates removing complexity from problems thereby implying that all problems present themselves and can be responded to in a similar linear manner. Systems theory advocates a very different approach from the reductionism approach. Thus, the Bhambayi study sought to

approach the problem assuming that it has many facets to it that cannot be resolved overnight. See the intervention discussion in Chapter 6).

Fig. 2.1, Five classes of systems (Checkland, 1981:112)

**Transcendental systems,**  
**beyond knowledge**

**Natural systems**

(Origin: the origin of the universe and  
the processes of evolution)

includes man, who can  
create

**Designed physical  
systems**

(Origin: a man and  
a purpose)

**Designed abstract  
systems**

(Origin: a man and  
a purpose)

**Human activity systems**

(Origin: man's self-  
consciousness)

According to Checkland (1981), there are different classes of systems, i.e. natural systems,<sup>8</sup> human activity systems, designed physical systems,<sup>9</sup> designed abstract systems<sup>10</sup> and transcendental systems.<sup>11</sup> Often, the expectation is the existence of a relationship between these kinds of systems. Fig. 2.1 is a draft representation exemplifying the five classes of a system.

The case study under review, '*Families of the Bhambayi community affected by HIV & AIDS*' can be regarded as a subsystem that displays in one way or another all of these class systems, i.e.;

- Natural systems: Ecological environment in which they live,
- Human activity systems: Social structures like local leadership,
- Physical systems: Infrastructure like housing,
- Abstract systems: Socio-cultural beliefs and mores, and

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<sup>8</sup> Originate from the universe and are a result of the forces and processes that characterise the universe.

<sup>9</sup> These sets of systems are designed with fitness of purposes in mind and are defined by Checkland as systems that "exist because a need for them in some human activity system has been identified" (Checkland: 1981: 119).

<sup>10</sup> These systems are an organised and ordered conscious product of a human mind, e.g. poems, cultural beliefs, philosophies etc. In most cases, abstract systems are less tangible than designed systems.

<sup>11</sup> This class of systems is beyond knowledge.

The *Systems Thinking* approach advocates that a variety of systems and objects related to a research problem be studied as wholes (Kay and Foster, 1999) and regarded as part of a larger system (community or society) that is made up of smaller systems (individuals or each family). According to the *Systems Thinking* approach, all these systems or processes are glued together into a whole that can only be fully understood if analysed in an interrelated manner – taking into consideration inputs, outputs, transformations and interconnections between the components that make up a research system under review. (See figure 5.1 tabulation). Advocates<sup>12</sup> of the systems approach urge problem solvers, decision makers and researchers to take full cognisance of the interdisciplinary, holistic character of the systems approach when attempting to understand and involve parties related to a research problem. They hold that the main objective should be to benefit all interested parties or stakeholders. The Bhambayi study applied this advice.

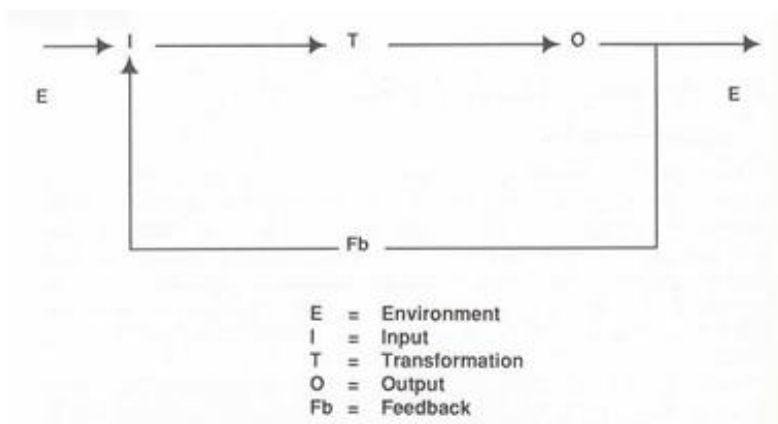
Churchman, (1968) and Ackoff (1974) describe the application of a systems approach to various situations, including social problems. Churchman, (1968) asserts that when applying the systems approach to analyse and understand a research problem, it is necessary to employ a model known as

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<sup>12</sup> In addition to scholars already mentioned in the discussion of the dissertation thus far, they include amongst others, Laarmans, 1999; Littlejohn, 2001; Midgeley, 2003; and Whitten *et al.*, 2004.

the input-output systems approach. Littlejohn (1999:13) terms this model a 'conceptual model' and represents it as shown in figure 2.2 below. The system (affected families) receives inputs (gendered socio-cultural beliefs and misconceptions about HIV & AIDS) which yield outputs (behavioural patterns that affect family members, subsequently affecting their well-being).

Fig. 2.2 Simple system model



Source: Littlejohn, (1999:12)

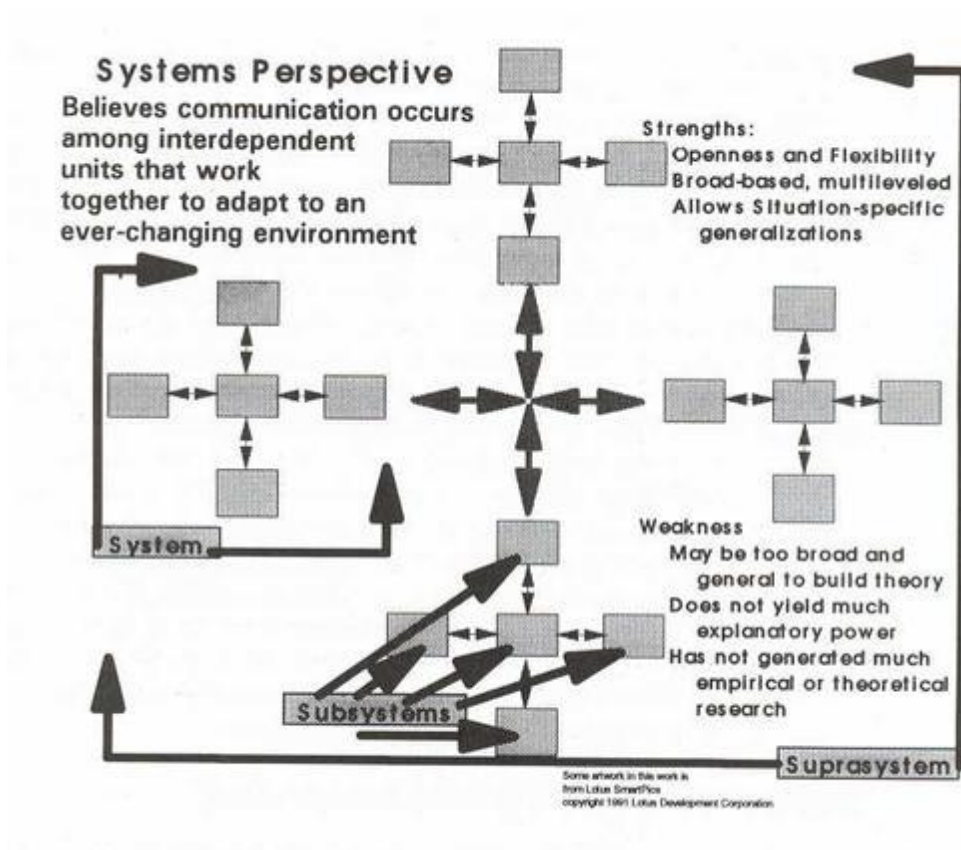
In summary, the main principles and expected behaviour of systems theory can be tabulated and graphically (see figure 2. 3) as well represented as follows;

- A system has physical or abstract (or both) kinds of element,

- A system consists of complex attributes,
- A system(s) is trans-disciplinary in nature and investigates the principles common to all complex entities,
- A system has internal relationships among its objects,
- Systems exist in an environment,
- A system has elements that affect one another within an environment and form a larger pattern,
- A system has continual stages of input, throughput (processing), and output,
- A system can demonstrate either openness or closed-ness. A closed system does not interact with its environment. It does not take in information and therefore is likely to weaken or die,
- An open system receives information, which it uses to interact dynamically with its environment and in turn increases its likelihood to survive and prosper,
- Several system characteristics are: wholeness, interdependence, and communication in this perspective are encouraged to allow an integrated process.



Fig. 2.3 Elaborated system perspective model



Source: Infante (1997) [Online]. Available from <http://www.managementhelp.org>. (Accessed 28 march 2008)

## 2.3 Soft systems methodology (SSM)

Hard systems<sup>13</sup> can be described as realistic and soft systems as nominalistic (Goede, 2005:99). It should be noted that whilst the Austrian philosopher, Karl Popper, amongst others, is associated with hard *Systems Thinking* approach, the work of Churchman (1968) and Ackoff (1971) is attributed as the foundation of the soft systems methodology. Whilst the hard systems approach does not always adequately define the problem, the soft systems approach views a system as a representation of the human mind to make sense of the reality (Dahlbom & Mathiassen, 1993). 'Where hard *Systems Thinking* views models as representation of reality, *Soft Systems Thinking* views models as aids for the development of inter-subjective understanding' (Goede, 2005:100). Goede, however, points out that soft systems methodology (SSM) has been criticised for supporting only one interest and failing to predict and control the environment. This study employs this kind of theory fully cognisant of its shortcomings as pointed out by Goede.

The principles of Systems Thinking approach listed in bullet points above are essential in an attempt to understand SSM. Further understanding of SSM

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<sup>13</sup> Checkland, 1981 uses the term 'hard systems' as an alternative to 'soft systems' and to refer to the kind of a system where a systematic process of problem solving is followed – with an assumption that the problem task is to select an efficient means of achieving a known and defined end.

and its enriched usage can, according to Flood (1999:75), be attained if the following characteristics of SSM are taken into consideration:

- The whole of an entity is taken seriously and the fact that it may exhibit unexpected or emergent properties,
- Using *Systems Thinking* is to set some constructed abstract wholes against the perceived real world in order to learn about it better,
- SSM uses human activity, a set of activities connected to a purposeful whole,
- Humans have an ability to interpret the world in different ways,
- Due to this ability, it is possible to create several models of complex human activity,
- The human activities are related and relevant to the whole.

*Soft Systems Thinking* attends to problems set in systematic pluralistic problem contexts. The Bhambayi families that are affected by HIV & AIDS are regarded as a 'system' that exists in such a context. I found that these families dealt with a number of complexities that are; directly related to HIV & AIDS, because of the disease as well as negative aspects of their socio-cultural and economic circumstances. *Soft Systems Thinking* argues that it is essential to begin with defining and stating the nature of a problem, as an initial attempt at understanding a problem. However, Checkland (1985), is

quick to warn that fixing a problem too early makes investigators unlikely to see different, more basic problems – hence Flood’s (1999) advice to keep the problem/ project vague and wide ranging for as long as possible. Flood argues that the process is more important than the outcome as SSM is not only just about intervention but can also help people make sense of the rough day-to-day affairs.

During the process of studying and engaging frequently with a case study I learnt and appreciated many variables vital to an holistic understanding of the Bhambayi case study. Soft systems methodology is therefore crucial as a way of tackling messy situations in the real world. SSM is based on *Systems Thinking*, which in turn enables a researched problem to be well defined and described (Ntiisa, 2007) before it is resolved. SSM is, therefore, both flexible and broad in scope and allows human beings (researcher and the researched) to attribute meaning to what they observe and experience in a much more meaningful manner.

In an attempt to provide assistance for researchers employing SSM in and for academic contexts, Checkland (1985) formulates seven stages (mode 1

of SSM) to act as an academic guide. Hereunder is my tabulation of the seven stages:

One: Existence of a problem that unsettles the norm and prompts people to want to resolve it.

Two: Expression of the problem situation is ideal at this stage. Checkland advises that rich pictures be used to express the problem better. Elements that can be used range from sketches, pictorial symbols to cartoons. Once the problem has been expressed, participants should ideally see their problem and environment in new ways.

Three: This stage is about systemic thinking in the real world. It involves naming human activities that may provide insight into the problem. During this stage, root definitions are developed and built around the view that advocates constitutive meaning underpinning human activity purposes. Checkland uses the mnemonic CATWOE<sup>14</sup> to describe the human activity and its situation. In chapter six this approach is employed to define and understand challenges faced by the study's participants as well as identify stakeholders 'holding' the key to transformation.

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<sup>14</sup> CATWOE refers to an analysis of a problem that concentrates on the process of a problem situation.

The acronym CATWOE is, according to Flood (1999:20) explained as follows:

C = Customers, i.e. victims or beneficiaries of the transformation process;

A = Actors, responsible for transformation;

T = Transformation process, conversion of input to output;

W = Worldview, context of the transformation process;

O = Owners, people with power to stop transformation process;

E = Environmental constraints that can affect the system.

Four: During this stage, there are further definitions and in turn conceptual models drawn up in an attempt to understand the situation of the problem better. Simple sets of verbs are used to describe the actions of human activity system.

Five: Conceptual models drawn during the previous stage are taken into the real world, i.e. now put against and compared to the actual problem situation (expressed in stage 2). During this stage participants put forward proposals about change.

Six: Proposals about change are discussed and deliberated on – taking into consideration elements of human activity that are

desirable and feasible. Equally considered is the broader context of the problem situation, i.e. attitudes and political nuances and interactions that dominate the problem.

Seven: In the final stage middle ground is sought between a variety of contrasting opinions and interests. Checkland (1985) refers to this stage as a time for 'seeking accommodation', whilst a fellow SSM advocate, Senge (1994:136) terms the stage a time for 'seeking consensus'. SSM critics argue that Senge's option is not practical as social problems are better dealt with if there is an acknowledgment that human beings are unique and perceive life differently. They assert that complete consensus is hard to reach.

The above discussion completes SSM mode 1. Soft systems methodology mode 2, argues Flood (1999), is an ideal conceptual framework useful for people wanting to make sense of their day-to-day experiences. Taking cues from Checkland (1985), Flood advises that we incorporate mode 2 into people's everyday realities. Flood then offers two kinds of analysis that are characteristic to mode 2 SSM; i.e.

1. Logic-based stream of analysis which persuades 'actors' in a problem to investigate the situation with the purpose of looking for new opportunities and ways to find accommodation between people, and, in turn, close any that may have existed between them because of diverse views regarding a problem; and
2. The conducting of a cultural analysis that is an holistic inquiry into a proposed intervention process or plan. This involves both social systems and political systems analyses. The cultural analysis demands: an exploration of the roles of stakeholders associated with the problem, social systems analysis and effect of norms and values on behaviours and exploration of how power dynamics of the political systems dictate or influence decision-making.

The importance of soft systems methodology for the Bhambayi case study can best be summarised by Cavallo's (1982: 72) discussion on the value of SSM for social science research:

(A)s a methodology that aims to bring about improvement in social areas by instilling a learning cycle that is never-ending for the people involved in the situation. This learning is accomplished through an iterative process of using systems concepts to reflect upon and debate different angles to the problem.



For the Bhambayi case study I opted to use SSM because of its relevance for HIV & AIDS, which is complex and requires the use of participatory learning in an attempt to allow people to better understand, and contribute towards improving their own situation.

## **2.4 Critical Systems Thinking**

'The world is fundamentally not harmonious', argues the school of critical thinking. (It is the Habermas (1974) philosophy that gave rise to this school of thought.) Consequently, in order to understand life phenomena and effect the necessary changes, it is essential to think in terms of contradictions within a context. Subsequently, it is to this end that critical systems thinkers advocate for an analysis of different perceptions and suggest a variety of interventions in order to find change/solutions that accommodate most stakeholders. Taking cues from the Harbemas theory, Jackson (1991), Midgeley (2000) and Mingers (1995) use the theory of 'three words' in support of the use of methodological pluralism to social problems. According to Jackson (1991:63), there are five major commitments to critical *Systems Thinking* i.e.:

1. Full awareness and demonstration of critical thinking, i.e. appreciating a possibility of existence of value in current and future solutions and therefore a need for a close examination of these variables including their strengths and weaknesses,
2. A critical *Systems Thinking* approach demonstrates social awareness and requires acknowledging societal pressures. Practitioners are required to study and be frank about possible consequences of their actions,
3. People are important hence the need for their emancipation, i.e. working towards maximum development of everyone's potential. This requires raising the quality of work and life in organisations and societies,
4. Critical *Systems Thinking* approach submits that all kinds of *Systems Thinking* could be useful in solving societal problems. In essence, it holds that different points of view of systems must be respected and accommodated,
5. Finally, it advocates that different kinds of *Systems Thinking* should not only be respected but also practically put into use to tackle social challenges.

In an attempt to understand the Bhambayi families that are discussed in this dissertation, the advice of critical *Systems Thinking* was taken into consideration.

Informed by Jackson's work, Goede (2005) presents a tabular summary of the differences between hard, soft, and critical *Systems Thinking* methodologies – listing systems ideas, role of models, use of quantitative techniques, process of intervention, and testing of solutions (see figure 2.4 below).

Fig. 2.4 Adapted summary of *Systems Thinking* methodology

<b>Hard Methodology</b>	<b>Soft Methodology</b>	<b>Critical Methodology</b>
Assumes real world is systematic	No assumption that real world is systematic	Assumes real world can be systematic & alienating to individuals and/ or groups
Problem situation analysed in systems terms	Problem situation is designed to be creative; may not be conducted in systems terms	Problem situation analysed to reveal who is systematically alienated or disadvantaged
Aims to capture the logic of the situation to gain knowledge of real world	Constructed models represent possible human activity systems	Constructed models reveal sources of alienation and disadvantage

<b>Hard Methodology</b>	<b>Soft Methodology</b>	<b>Critical Methodology</b>
Models used to learn how best to improve real world	Models used to interrogate perceptions of real world and debate about feasible and desirable changes	Models used to 'enlighten' the alienated and disadvantaged and suggest possible improved arrangements
Quantitative analysis and mathematical laws highly regarded	Quantitative analysis is not put first, only useful to clarify implications of world views	Quantitative analysis may be useful to capture biases in existing systematic arrangements
Process of intervention is systematic and aimed to discover best way to achieve a goal	Process of intervention is systematic, never-ending and aimed to alleviate unease about problem situation	Process of intervention is systematic, never-ending and aimed to improve problem situation for the alienated and disadvantaged
Intervention is conducted on basis of expert knowledge	Intervention is conducted on the basis of stakeholder participation	Intervention is conducted to maximise chances of the alienated and disadvantaged taking responsibility for the process
Solutions are tested primarily in terms of their efficiency and efficacy	Changes that might alleviate feelings of unease are evaluated primarily in terms of their effectiveness. Elegance & ethicality	Changes designed to improve position of the alienated and/ or disadvantaged if evaluated in terms of ethicality and emancipation

Source Jackson (2001) in Goede, 2005:105-106.

## **2.5 Social constructionist theory**

The social constructionist theory, a sociological set of principles, is one of the ideological foundations that informed this study. The social constructionist theory emerged in the late 1960s, developed by Peter Berger and Thomas Luckmann. It sets out to focus on uncovering the ways in which individuals and groups participate in their perceived reality. In essence, it examines the manner in which a social phenomenon is created, institutionalised and made into tradition by humans (Wikipedia, N.d). Bilton *et al.* (1996: 200) define social constructionism as 'the process whereby 'natural', [and] instinctive forms of behaviour become mediated by social processes...and in this way [become] socially constructed'. Predominantly, society and its social institutions, arrangements and conventions thus predate people and box them into pre-defined identities of feminine and masculine. Along this thinking are the gendered roles that accompany these identities which are either taught or learnt.

Using the social constructionist perspective elsewhere (Meyiwa, unpublished), I argue that mothering choices indicate society's expectations of a mother: she is expected to give up everything in the interest of her children, irrespective of her personal beliefs, likes and preferences. The Bhambayi study found that such personal sacrifice extended to taking a

decision not to have a sex partner. According to the social constructionist theory, the participants (mothers and caregivers) also have a role to play in what happens in their lives. 'A constructionist perspective maintains that individuals are meaning constructors and the significance of those meanings must be understood as contextually embedded' (Schwandt 1994, quoted in Thompson, 2000: 156). Despite the fact that five of the six main research participants (caregivers in the study) did not give birth to the children they look after, they term their role as mothers and call themselves mothers, an indication that the practice of motherhood in Africa is changing in the 21<sup>st</sup> century. The activities of the care-givers, be they a biological mother, or a grandmother, or a great-grand mother, a male guardian or an institutional foster mother, demonstrate the special significance each 'mother' attaches to his or her role.

What is closely aligned to social constructionism is a process of socialisation which is the process through which these culturally mediated norms, values and identities are learnt. Bilton *et al.* (1996: 205) describe it as 'an on-going process whereby individuals learn to conform to society's prevailing norms and values'. In this socialisation context, at a very early age, boys and girls unconsciously learn expectations of their different sexes. To entrench this, reinforcement is given in terms of praise and applaus. These 'awards' are

given to those who conform, while punishment by either physical or verbal retribution or societal ostracisation is meted out to deviants. Alongside this socialisation exists processes of modelling or imitation copied from parents or older members of society which serve to internalise taught behaviour. Cultural and/or traditional values are also used as a spring-board for learning attendant gender roles (Shikumo, 2008).

On studying some Bhambayi family members' statements, I found that some participants alluded to and acknowledged the key role that cultural beliefs initially play in building up one's worldview. It is therefore clear that the belief systems that are formed are hard to shake even in the face of an alternative and an environment that is modern as well as progressive-seeking. The use of this theory therefore enables a deeper interrogation of how some identities are reinforced or maintained, newly acquired, questioned, changed or completely abandoned in the face of personal introspection. This theory therefore is found to be most appropriate in explaining why it becomes harder to scrutinise some of those gender-based caring roles that may be negative due to an internalisation and acceptance of them as the norm or standard. In most Zulu-speaking families specifically, as part of their socialisation, children learn from a very young age to participate in the domestic role of their male or female parents. They are

therefore socialised into the traditional gender role patterns in their families. Kayongo-Male and Oyango in Sokoya (2003) submit that the most remarkable characterisation of socialisation in the African family is the large number of agents of socialisation. 'Grandparents are important agents of socialisation in traditional African societies; and they are more instrumental in introducing young people to sensitive topics such as, husband-wife relationships and sexual behaviour, as well as societal roles, values and tradition (Sokoya, 2003: 144). This, they often do through the medium of folk stories, proverbs and songs. Some advocates of this theory thus subscribe to the notion that, social conditioning and socialisation processes, as espoused in social constructionism, point at identity formations that define gendered identities of the self (Bilton *et al.*, 1996 and Thompson, 2000).

Stockard and Johnson (1980: 103) emphasise that 'the basic gender characteristics of the sexes are learned in the family environment very early in life and are then reinforced in the schools, in peer groups, in the mass media and many other specific agencies...'. This highly structured 'schooling' makes female and male children effectively and quickly learn their roles and thus define their agency in society. Some of the Bhambayi study's participants acknowledged their complacency in passively accepting some



roles and identities because of taught and entrenched behavioural and identity patterns. Robertson (1987) in Shikumo (2008: 89) points at three psychological practices and processes through which children learn to internalise trained roles:

1. Conditioning – This process is conducted through rewards and punishment, usually in the form of parental (and to a large extent, societal) approval or disapproval;
2. Imitation – In this process, young children tend to imitate older children and adults, and are more disposed to imitate those whom they regard as most like themselves. The older children and adults would have similarly gone through gender socialisation processes in most cases; and
3. Self-definition – Through social interaction with others, children learn to categorise the people around them into two sexes and to label themselves as belonging to one sex rather than the other. Children subsequently use this self-definition to select their future interests and to construct their personalities and social roles.

A study of the literature thus revealed that gender-role stereotypes have a major influence on the construction of research participants' gender roles and identities - which are then subsequently reinforced later in various ways and at different places in society and community life. Gender role

socialisation and gender division of labour in families were also found to have a strong influence on gender construction. Besides the family structure, other social institutions can easily provide an avenue for consolidating different gender identities and roles mostly arising from peer pressure or the absolute need to conform and be better accepted by one's family or society.

Kimmel (1987: 12) decries the societal 'sex-role' models that 'specified the ways in which biological males and biological females became socialised as men and women in particular cultures'. The socialisation process in family systems of the Bhambayi case study is believed to be central to the construction of gender and gender role identity. Assigned sex roles use explicit biological or anatomical difference in men and women to define their roles. Put crudely, the fact that women have a vagina would thus be automatically interpreted as a reproductive function whilst the penis for men would symbolise authority if one gives it a phallocentric reading. This study argues that care giving and the concept of mothering and/ parenting are social constructs. Thus they should be defined as a 'gendered phenomenon' (Magwaza, 2003)<sup>15</sup> that has come to be associated with and refers to how

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<sup>15</sup> Electronic source Available from [www.jendajournal.com/jenda/issue4/magwaza.html](http://www.jendajournal.com/jenda/issue4/magwaza.html). (Accessed November 29 2006).

these constructs come to be characterised. A number of scholars<sup>16</sup> comment on various socially constructed collections of assumptions, expectations and ways of behaving that serve as standards for forms of male behaviour and thus point to a strain of social constructionist theory where gender identities and roles are viewed as a product of social encounters and relationships. In a salient manner, these gender scholars reiterate the fact that human beings largely acquire certain traits and characteristics through repeated indoctrination. Accordingly, Butler (1990: 8) argues:

If sex, as well as gender, is a construct, it follows that the body does not have a pre-given essential sex. Rather bodies are rendered intelligible through gender and cannot be said to have a signifiable existence prior to the mark of their gender. Bodies become gendered through the continual performance of gender.

Evans (2003) concurs and points out that we acquire our gendered selves through socialisation, and the internalisation of social expectations. In the Bhambayi study, the social expectation measurement is observed not only with established perceptions about care giving but also with associating the practice with motherhood and in turn regarding primary male care-givers as 'mothers'. Male caregivers thus report that their identity as being wholly

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<sup>16</sup> Listing a few, see Connell, 2005; de la Rey, 1992; Evans, 2003; Makhaye, 2005; Morrell 2001; and Ngcongco, 1993.

male comes to be questioned by (some) family and community members. They are therefore seen as effeminate and lacking the full measure of masculinity. Bilton *et al.* (1996: 200) note:

Gender differences derived from social and cultural processes create systems of ideas and practices about gender that vary across time and space. They also create gender divisions of labour, allocating men and women to different activities and responsibilities. Individuals raised within such a framework will come to have appropriately gendered identities and desires.

Significant and central to the thesis of this dissertation is an argument put forwarded by Burr (1998: 13) that offers a place for the re-constituting of socialised gendered activities and roles. Burr proffers a case for what she terms 'constructive alternativism' which situates the idea that there exist a potentially infinite number of alternative constructions of events - in this case, socialised norms and values.

To this end she submits:

If we take ourselves and others to be constructions and not objective descriptions, and if it is human beings who have built these constructions, then it is [at least in principle] possible to re-create

constructs of ourselves in ways which might be more facilitating for us (Burr, 1998:13).

Taking into consideration the social construction theory's arguments, the Bhambayi study advances Burr's submission and acknowledges that both women and men cannot be viewed as passive but rather active agents that are involved in the constructions of their identities and thus have a choice as to what beliefs they will internalise as well as behavioural patterns they will adopt.

As regards getting more men on board as care-givers in the challenging context of HIV & AIDS, there appears to be a dialogue of sorts between men and cultural messages in which they come into contact. They appear to be constantly negotiating with, influencing, appropriating, or resisting change. Men can be encouraged to take a more participatory interest in what has been traditionally regarded as a woman's role, i.e. providing care within the family. According to Lobner (2001: 26) gender stratification, stereotypes and prejudices observed from 'cultural constructionism character' provide a powerful means by which different genders are either recognised or devalued. 'These categorical imperatives govern our lives in the most

profound and pervasive ways, through our social experiences and practices' states Lorber (2001: 28). The fact that our worldview is arranged from this nurturing and socialisation makes it an important consideration in addressing gender inequality due to its pool of power.

Reiterating Lorber's view, de la Rey (1992: 78) contends that: 'So much of how we choose to live is an enactment of cultures and traditions which take gender-specific forms'. Cultural gender insensitivity plays out in the way our traditions and rituals attach significance to certain significant landmarks in our lives as human beings that give succinct distinctions to the importance (or otherwise) of being either male or female. Rituals and traditions accompanying birth, puberty and adolescents, sexuality, sexual relationships, marriage and even death inscribe in us gender-specific cultural identities and attendant roles. South Africa, a multicultural society has a myriad of traditional African cultures, Indian cultures and White culture that has its roots in Western culture. Even within African cultures there is still a dynamic mix of Xhosa, Zulu, Sotho etc. traditions. de la Rey (192: 85) however notes that: 'While there are differences in the specific practices, there are gender-related features that our backgrounds have in common; for example, there is evidence that women are undervalued and anything associated with women seems to be evaluated negatively'.

The cultural construction of gender in a particular society involves defined roles that are given to both men and women. The positions entrusted to men include head-of-the-house, elder/chief, custodian and enforcer of specific traditions, warrior, decision-maker etc. Care giving and parenting are not listed amongst these positions. In turn, as it was found with the Bhambayi case study, roles from this list prescribe certain identities and behaviour patterns that, erroneously, are represented as being inherent, natural or biologically-given.

Social construction of masculine identities through cultural prescription works through various mechanisms using rituals and taboos. As earlier discussed in the above discussion, these identities are enforced through a system of rewards and punishments. Most taboos lay down what punishment is given to disobedience. In most African societies rituals accompany the formation of gender identities. These rituals, such as male circumcision, effectively detach boys from women (mostly mothers and sisters) with whom they may have shared the first six or seven years of their lives. Whilst the initiation ceremonies for the males carries much pomp and ceremony, for the women, '...the transition to womanhood is often part of a more subtle

and continuous process of enculturation and socialisation' Brettell and Sargent (2001: 158).

The above discussion on cultural prescriptions of masculine identity through various rites in no way legitimates the assumption that those circumcised or 'ritualised' will automatically follow through with actualising the given identities. Lorber nonetheless points out that 'most people, however voluntarily go along with their society's prescriptions for those of their gender status, because the norms and expectations get built into their sense of worth and dignity' (Lobner, 2001: 28).

## **2.6 Grounded theory**

This qualitative research methodology and ideological underpinning was used in the study to examine the experiences and reality that face Bhambayi families affected by HIV & AIDS. The grounded theory was decided upon as a suitable ideology to employ in understanding and analysing the lives of the families, and how variables in their reality intersect<sup>17</sup> to inform their lives in relation to care giving and parenting. Grounded theory techniques are useful in contributing to a knowledge base that has not been subjected to much

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<sup>17</sup> This is also a *Systems Thinking* way of approaching a problem.



formal inquiry and about which little is known. Although a number of studies on care-giving and parenting have been conducted in the context of HIV & AIDS, at the time of conducting the Bhambayi research I was not aware of any study done with a specific focus on intersections between care giving, HIV & AIDS and the changing concepts of family and motherhood in this context - and in particular, none was conducted in the research study area of focus, Bhambayi. As such, the grounded theory is a method that allows for flexibility which was required for the exploratory nature of this study. As Glaser and Strauss (1967: 32) point out, it is a method that frees one to 'discover what is going on, rather than assuming what should be going on'. Accordingly, the qualitative holistic approach of ground theory served as a valuable heuristic in understanding and explaining what caregivers and family members go through in their efforts to deal with HIV/ AIDS.

Corbin and Strauss (1990:5) define the elements of grounded theory thus:

- Incidents, events, and stories that make up people's lives are taken as, or analysed as, potential indicators of phenomena they deal with
- The researcher's task is to relate the incidents listed by research participants to the objective of the study. My task was to relate the stories, told by both the learners and other people in their lives, to

the holistic life experiences and strategies of the caregivers in dealing with the HIV & AIDS pandemic

The other element of grounded theory is defined by Corbin and Strauss (1990: 7) thus:

Categories are higher in level and more abstract than the concepts they represent. They are generated through the same analytic process, of making comparisons to highlight similarities and differences, that are used to produce lower level concepts.

Taking into consideration systems approach and in the context of the Bhambayi study, this element was understood as the need for me as a researcher to understand various details that are given by research participants and to categorise them into chunks of shared experiences; for example a resolve not to disclose one's or a family member's HIV status due to the fear of being stigmatised through alienated and being the victim of the misconception that once a positive HIV status is established it is a declaration of a death sentence, etc.

## **2.7 Feminist perspectives and rights-based theory**

Feminist theory aims to comprehend the nature of gender inequality and focuses on gender politics, power relations and sexuality. While generally providing a critique of social relations, much of feminist theory also focuses on analysing gender inequality and the promotion of women's rights, interests, and issues. Themes explored in feminism include discrimination, objectification, especially sexual objectification, oppression and patriarchy. In the Bhambayi study, data was analysed to understand how these aspects impact both men and women affected by HIV & AIDS. The general finding was that women (or mothers), rather than boys (or fathers), are intensely exposed, affected and more affected by HIV & AIDS due to their gender. In the context of this study there is a need to highlight gender imbalances in the manner advocated by some key feminist activists and scholars listed below.

The struggle against gender inequality has a long history. It dates back to early feminist struggles as recorded by the likes of Betty Friedan of the first wave, her bone of contention was the suffragette cause and women's exclusion from the vote, to Mary Wollstonecraft's (2<sup>nd</sup> wave) main charge relating to women's exclusion from the public, political, social and economic domain and consequent relegation to the private sphere, and agitation for

their sexual freedoms. This was followed by modern discourses in the 21<sup>st</sup> century that include eco-feminism and earth democracy as articulated by the likes of Vandana Shiva (3<sup>rd</sup> wave). Nonetheless, in all this re-structuring, women's subordination has been masked in patriarchy. Spender (1982: 5) equates it to a question of men always being in charge. She states:

Men are in charge in our society, not only do they hold the most influential positions and own and control most of the resources, but their positions and resources enable them to ... make pronouncements on what makes sense in society and what is to be valued.

Given this exclusion, feminists subsequently began challenging sex roles and gendered identities that defined men as superior and women as subordinate. Their point of reference was that 'male-identified roles were frequently seen to be more important and deserving of greater social rewards than female-identified roles' (Steans, 1998: 11). It was realised that the status accorded to both sexes was not equal. What had seemed to be natural in terms of men being more 'aggressive, objective and logical [as opposed to women being] more passive, emotional and sensitive' (*ibid.*) was queried. It was concluded that such illogical gender apportioning had been used to justify women's subordination over the years. The struggle against gender imbalances has been informed by the knowledge that hierarchies established

within pronounced masculine and feminine roles helped to consolidate the imbalanced status by way of rewards or societal affirmation and approval. Patriarchal systems continue to impress upon women that 'a good woman cooks and does laundry for her husband, she sees it as her husband's right to make major family decisions, she may not argue with him, nor want access to the kind of benefits or pleasures he does' (Ngcongong, 1993: 6). In this (mis)construed way, women strive to stay in their 'place' in respect to the phallic superiority and in turn unconsciously pass on a trend to be followed by their girls. Cognisant of the existence of a new global wave of attempts to accord girls and women the human rights they deserve, feminists have been taken aback by such drives and in turn acknowledge that within the feminist struggle, there are those that endorse the entrenchment of patriarchy by methods of divide and rule amongst women organising to challenge the imbalanced status quo as having worked to propagate patriarchal agendas. Spender (1998: 24) notes:

I am going to suggest that patriarchy has found it profitable to turn us away from the intellectual. We have been discouraged from formulating and building theories, for patriarchy finds this a dangerous activity on the part of women. This is why the theories we have constructed, again and again, and which show many similar features, have so effectively disappeared.

## **2.8 Indigenous knowledge Systems Thinking**

With the advent of democracy in South Africa, the government, composed largely of indigenous South Africans, came into power. The government has been at the forefront of the struggle of 'resuscitating' the dignity and the heritage of its indigenous peoples. Within the country the IKS research approach strengthened due to such a 'renaissance agenda'. Taking lessons from the past in order to live a meaningful and beneficial life for the individual and community forms one of the approaches of the discipline. Emanating from this principle, for the Bhambayi study, I was encouraged to investigate and draw attention to continuing practices of the past amongst indigenous peoples. The IKS research paradigm maintains that, with such a conscious research approach, researchers can contribute towards the excavation, preservation as well as knowledge generation of indigenous people. It also argues for a research practice that allows for story telling strategies and mode of investigation of the oral tradition and indigenous knowledge.

A number of scholars have made a bold contribution towards the development of the indigenous knowledge systems as an academic site of enquiry. Most publications, however, are a range of scanty ethnographic and anthropological literature. A few are worth mentioning: A journal edited by

Edgard Sienaert, Sienaert Sienaert *et al.* (1991) that emanated from selected conference papers, *Indilinga*,<sup>18</sup> presents varied perspectives on and approaches to indigenous knowledge research – stressing the interdisciplinary nature of IKS. Articles of note from this journal are presented by Zacarias Ombe and Solvi Lillejord and Gunn Soreide. Ombe indicates the manner in which indigenous knowledge serves as a fundamental and builds upon the historical experiences of the Changane people (his case study). He argues that the Changane people's IKS has adapted to social, economic, environmental, spiritual and political change. On the other hand, Solvi Lillejord and Gunn Soreide point out that personal and group narratives are essential as a resource for an inductive understanding of a people's culture. Furthermore, they provide guidelines on interpreting interviews as well as 'narratives within narratives'.

For IKS scholars, foregrounding indigenous languages is a major concern, with the claim that the interviewers' actual vernacular words and/ or their cultural beliefs should appear in the research report or publication. They hold that this practice assists in the preservation of the languages that are slowly dying out; in particular, the San languages of South Africa. Although the IKS

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<sup>18</sup> African Journal of Indigenous Knowledge Systems, Vol. 2 No. 1 published in June 2003.

approach was used for the Bhambayi study, I purposefully did not follow this advice as I translated all the data collected in the Zulu language into English.

Given an often long history of disregard or misrepresentation of the indigenous peoples, researchers are urged to treat the interviewees as partners both in the processes of investigation and knowledge generation. I hold that the IKS research approach is based on principles and values that resonate with feminist research, hence its inclusion as one of the tools used to further understand the Bhambayi case study.

## **2.9 Chapter summary**

In this chapter multiple theories are described and their value for the study highlighted. Although the theories seem diverse at surface value and derive from distinct schools of thought, their commonalities and relevance for the study outweigh how they developed and the fact that they are often applied differently. The discussion in the chapter 'speaks' of the different theories under a single continuum termed *Systems Principles*. In essence, this chapter serves as the backbone of the study and discussion of the dissertation because it provides the framework within which the research problem was approached and analysed. Strategies derived from the theses



put forward by the framework form a premise for possible solutions towards the problem. Chapter two can thus not be read in isolation from chapters five and six. These chapters are actually the analyses, application, contextualisation and justification for the value of theories, (i.e. *Systems Principles*) of the study discussed in this chapter.

# CHAPTER THREE

## Social research practice

### 3.1 Introduction

Methodology is an interface between methodological practice, substantive theory and epistemological underpinnings (Harvey, 1990:132). Taking cues from Harvey, I conducted this research taking into account that these crossing points, though often distinctively presented in research reports, interconnect in social science practice to offer insight into a case under study. A myriad of social research methodologies and practice was used in this study against the backdrop of feminist research practice and organisational *Systems Thinking*. It should, however, be noted that this study does not delve deep into or use a comprehensive suite of elements of any one kind from the social research methodology.

### **3.2 Ethnography and reflexivity**

A researcher has an option to be an outside observer or to be actively involved in a case study through participant observation or action research. I decided to adopt the latter approach which necessitated the use of ethnography and reflexivity approaches. Substantially, principles of feminist research methodologies guided the study. In particular, the study was influenced by Bowles and Klein's (1983) discussion on essential principles that a feminist research project needs to consider. In line with the authors' recommendations, the dissertation presents the caregivers' experiences, understanding and conceptualisation of their own practices as well as experiences as they were directly communicated to me.

#### **3.2.1. Ethnography**

The goal of this approach, asserts Agar 1980, is to reduce the gap between the researcher's account of the situation and that of a recipient in the situation. In an attempt to honour this principle, I was personally involved in the study of the Bhambayi families with my role somehow equal to what Goede (2005) refers as the 'status of a child' – where the researcher has a direct personal contact with the participants. I continuously sought to learn

from the participants with the intention of wanting to improve my understanding of their situation as a whole. During the intense study period I practically 'stayed' at Bhambayi, spending the greater part of the day (7 a.m. – 9 p.m.) with the families under study or in the environment they live in. When I was not talking to them I would be conversing with other members of the community, attending functions in the area ranging from church to political meetings or helping out at a government-funded care centre for orphaned children. This engagement allowed me to be able to restate events of the Bhambayi community. Alongside this involvement was the awareness reflexivity.

### **3.2.2 Reflexivity in the study**

The participants' lived experiences are either presented in the discussion of the dissertation in the best for possible. The discussion, to a limited extent, is also based on reflexivity<sup>19</sup> and the analytic attention of my role as a researcher and a foster mother of an adopted child who is HIV positive. Reflexively, in this dissertation, I include these roles of myself in most stages of data collection and data analysis. Self-reflexivity forms a vital part of this dissertation as I equally record my emotions as well as feelings coupled with reactions of the respondents to the questions posed to them.

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<sup>19</sup> First conceived by Gouldner (1971).

My subjectivity as a researcher could not be avoided. It did not only play a significant role in the conceptualisation of the study but was also crucial during the data gathering process. Also, as a foster mother I could relate very well to some of the respondents' articulated experiences. As feminist research scholars urge, reflexivity in this study meant that I had to acknowledge my knowledge and experiences but equally engage with respondents' stories. Gavin Sullivan notes that it is necessary for a researcher to recognise the impact of language, theories and experiences that co-create phenomena that are studied. He then urges,

It is important that we continue to be reflexive and subjective in our research in ways that cannot easily be dismissed as biased and anecdotal. Research (needs to) draw, as it must, on our experiences as individuals who live and grow in one part of the global city of language, while recognising that we cannot live as individuals in every suburb. (Sullivan, 2002: paragraph 28, <http://www.qualitative-research.net/fqs-texte/3-02/3-02sullivan-e.htm>).

In an attempt to deal consciously with the negative aspects<sup>20</sup> of reflexivity I would pose a question differently after a response was given and would begin an analysis of a response given by asking, 'Do you mean ...? (I would then give my interpretation)'.

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<sup>20</sup> Such aspects include but are limited to researcher's preconceived ideas and interests (Sullivan 2002).

It was interesting and humbling that on a couple of occasions respondents would refute my analysis and give an alternative interpretation.

### **3.3 Critical social research**

The study also applied critical social research, in the manner advised by McAllister (2002). This allows for sensitivity and respect for study participants. This kind of research consciously accommodated feminist critical epistemological positions, i.e. it made all attempts to minimize power relations and feelings of unease between the researcher and participants. To apply this kind of research approach, repeated visits were made to Bhambayi, with the purpose of getting familiar with the area of research. This was before embarking on empirical investigations that involved interviews and probing.

Critical social research is a kind of research practice that necessitates strong interpersonal skills and an opportunity to draw from one's experiences. I found that as a mother I could relate to some of the experiences and feelings of the participants to those of my own. Harvey (1990:78) holds that whilst relating to some of the experiences, the approach allows the researcher to maintain his/her own identity and to be truthful about who

he/she is as well as the biases she brings to the research problem. I found that using this kind of a research approach made me gain better access to participants and their stories. Critical social research also allows for a process of building meaning and interpreting data in order to take effective and informed actions for change.

### **3.4 Interpretive social research**

The key assumption of interpretive research is to start off with the premise that access to reality (whether it is given or socially constructed) is only possible through social constructions such as language, consciousness and shared meanings (Boland, 1985). Following cues from Kaplan and Maxwell (1994), the study adopted interpretive research with an attempt at getting an understanding of the research problem from the context within which it operates. For the purpose of this study, this approach was aligned to the system's approach of highlighting the importance of taking into consideration the environment in which the Bhambayi people operate as well as the complexities and dynamics that exist in their neighbourhood and cultural background.

The context or environment of a research problem is taken as an essential social reality from which 'proper meaning' of the situation can be explored or achieved. Having closely studied the environment of a research problem, and gaining information of the research area allows the researcher to infer and/ or provide information that further assists in gaining a better understanding of the studied people and their experiences.

### **3.5 Methodology: Gathering data**

The Bhambayi study was empirical and qualitative in nature. I conducted 15 in-depth interviews with mothers or care-givers of children whose parents had either died or were in an advanced AIDS stage. Given that data kept on repeating itself, the number of participants was ultimately cut down to six so I focus solely on six individuals. The other nine participants were excluded because their characteristics were found to be similar to those of the six on which I report, for the purpose of this dissertation. All the interviewed mothers were Zulu speakers, one of the main languages of the country and one spoken by the majority of the people who reside in Bhambayi. All the mothers were interviewed in Zulu in their own homes. Excerpts from the Zulu transcripts were later translated into English.



A minimum of two sessions of semi-structured interviews, lasting between two to four hours, formed the basis on which the data for this chapter were collected. The focus on investigating the main participants' experiences and perceptions lasted about seven months with visits every so often. Preceding these months and this focus, I had had dealings with all the participants under the auspices of a larger project which focused on the aftermath of the HIV & AIDS scourge. Thus, gaining their trust and confidence for the purpose of this study was not a difficult task. The nature of the interviews allowed the mothers a degree of flexibility to lead as well as to define key topics which they felt at ease to talk about. All participants gave permission for their information to be used for publication purposes, but without making public their family pictures and names. For this anonymity the study employs pseudonyms.

The interviews were not tape-recorded, as there was general unease about 'our voices and personal stories being shared with people we do not know.' 'We do not want our children to be taken to the world!'<sup>21</sup> These were some of the responses received when I requested to use the participants' identity characteristics. In turn, hand notes were meticulously taken, which later

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<sup>21</sup> These were some of the concerns expressed by the participants.

needed to be validated at a second or third meeting with the mothers. Such subsequent meetings were considered crucial for this purpose.

### **3.6 Data analysis and interpretation**

For interviewing purposes and data consideration, an exclusion criteria was used, women who were not South African citizens and who had not at least lived in the country for ten years were excluded from the sample. The decision to set ten years as a bench mark was adopted considering that the country's democracy is fifteen years old and the women would have a first-hand experience of both the old and democratic regimes. In addition to the fact that women selected had previously had contact with the research, the focus of the study and sample inclusion, involved only women who had at least a higher primary school qualification and willingly availed themselves for interviews and email and/or face to face discussions during the research period. The respondents I engaged with, as they were promised, remain anonymous.

### **3.7 Chapter summary**

In this chapter the discussion has been on the methodological pilgrimage used in collecting the Bhambayi families' data. It explains the approaches adopted, the reasons for adopting them as well as their relevance in better contextualising collected data. It is a foreground to HIV & AIDS issues presented and discussed in the next chapter.

# **CHAPTER FOUR**

## **Care-giving and HIV & AIDS issues**

### **4.1 Introduction**

This chapter gives an overview and highlights extent to which HIV & AIDS has spread over the years. It provides some statistics for the reader to appreciate the magnitude of the HIV & AIDS problem in KwaZulu-Natal; these figures confirm the fact that there is a need for studies of this nature. Furthermore, the chapter discusses some principles and issues that have served as a framework for understanding and contextualising the Bhambayi case study. Whilst on the one hand the discussion has elements of what can be loosely regarded as academic theories and principles, on the other hand it presents concerns and issues that commonly beset projects related to care-giving generally and for HIV & AIDS cases specifically.

## **4.2 HIV & AIDS: A general overview**

Since its advent in the early 1980s, the HIV & AIDS epidemic has proved intricate thus indicating that dealing with the disease cannot be achieved by the use of linear or mono-disciplinary approaches (Campbell, 2005). Advocating for changing and multidisciplinary means of understanding the disease, how it manifests itself and how it can be overcome, is apt. This complexity calls for putting in place a systematic plan in which an intervention for development purposes could be undertaken. This dissertation attempts to do that, by exploring and suggesting a number of ways through which the epidemic and its impact can be understood. Given the weighting of the dissertation and that it is part of a small portion towards the MA degree; I provide a brief overview description and analysis of the research problem and do so with what I regard as key aspects of HIV & AIDS and care-giving issues.

Although chapter one, (the introductory section of the dissertation) provides some background information on the disease and the Bhambayi area, in this section I have put into context the basis and complexities within which the Bhambayi case study rests and ought to be understood. Seeking to provide a broader context, this section thus briefly describes the geography & demography of the KZN province, the epidemiological situation of HIV &

AIDS, the impact of HIV & AIDS as well as some determinants of the epidemic. In an attempt to provide an accessible overview of the disease, its comparisons and trends, this section lists statistics in the form of graphs and tables.

### 4.3 KwaZulu-Natal (KZN): HIV & AIDS status quo at a glance

KZN is the most densely inhabited province in South Africa. It is reported to have 21% of the country's population. According to *Statistics South Africa* mid-year (2007) about 10,014,500 people (see Figure 4.1) reside in the province. Its sexually-active population accounts for 59% of the total population; 54% of the 10,014,500 population live in the rural areas. In contrast to the urban areas, poverty and disease make conditions in the rural and peri-urban areas like Bhambayi difficult thus presenting insurmountable challenges to combating HIV & AIDS.

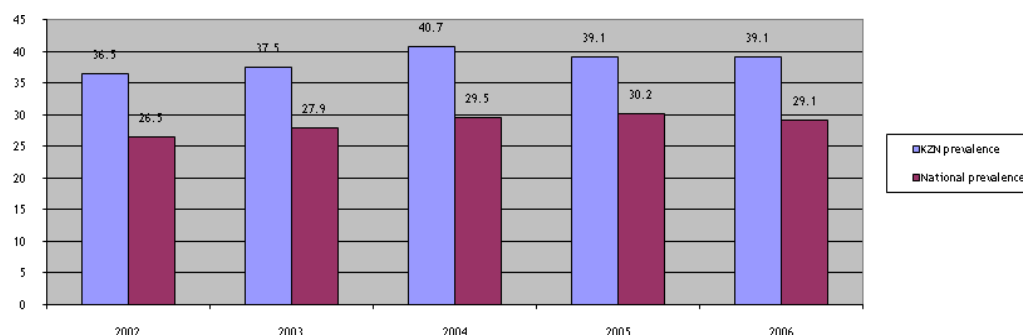
Fig. 4.1 KZN Population by Age Group (mid-year 2007 estimates)

Age Group	Population			Age Group	Population		
	Male	Female	Total		Male	Female	Total
0-9	1,136,300	1,126,600	2,262,900	40-49	384,200	475,300	859,500
10-19	1,145,100	1,133,900	2,279,000	50-59	236,200	304,300	633,700
20-29	964,460	967,000	1,931,600	60+	183,000	280,000	463,000
30-39	648,100	684,800	1,332,900				

Source: *Statistics South Africa Statistical Release Mid-year Estimates, 2007*

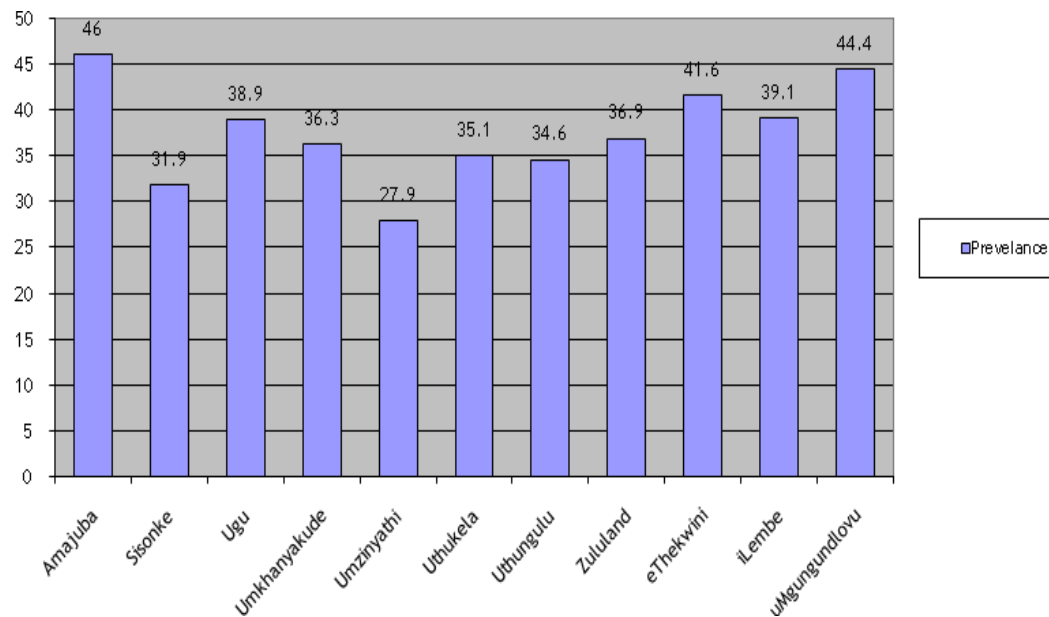
Reporting on the status of the pandemic, the KwaZulu-Natal Provincial Department of Education *HIV & AIDS Strategy 2007-2011* (2007:3) document reports that, '(t)he antenatal prevalence has consistently been higher than the national antenatal prevalence for the past five years. The KZN average prevalence over the last five years has been 38.5% as compared to the national average of 29.1%'. As exemplified in figure 4.2, specific district antenatal prevalence for 2006 ranges from 46% in the Amajuba district to 27.9% in the Umzinyathi district. Citing the country's Human Science Research Council survey report of 2005, the KZN strategy document submits that of a total of 1, 563, 749 people infected by HIV, 1 533 516 of this number were black South Africans.

Fig. 4.2 KZN Antenatal HIV Prevalence vs. National Prevalence, 2002-2006



Source: Graph compiled with information from *National Department of Health Antenatal Surveys, 2002-2006*.

Fig. 4.3 Antenatal HIV Prevalence by District, 2006



Source: KwaZulu-Natal Provincial Department of Education *HIV & AIDS Strategy 2007-2011*.

Conducting a national household study of all nine provinces of South Africa, the HSRC (2005) found alarming statistics relating to KZN. It notes that of all the country's orphans and other vulnerable children, KwaZulu-Natal has the highest percentage of 2–18 year-olds who are orphaned. A total of 19.7% children are orphaned. 'Though not all are necessarily AIDS orphans, it is believed that a large percentage is attributable to HIV & AIDS' (The KwaZulu-Natal Provincial Department of Education *HIV & AIDS Strategy 2007-2011*, 2007:6).



Fig. 4.4 HIV Prevalence by Age & Sex, 2005

Age Group	Prevalence		
	Male	Female	Combined
2-14	11.5	3.7	7.9
15-24	8.3	23.3	16.1
25-34	18.9	41.5	34.3
35-44	32.0	20.4	24.1
45+	12.8	7.0	9.2

Source: NMF/HRSC Survey, 2005.

These statistics corroborate those of Ren (2006). They are not only worrying but are an indication of the negative impact HIV & AIDS is having in KZN generally and on its communities specifically. It should be noted that, economically significant groups, e.g. adults, parents and the KZN workforce fall within the sexually-active population – a form through which the disease is largely contracted in Africa (Campbell & Foulis, 2002 and Tallis, 1997). It is thus apparent that with the high prevalence and increasing mortality rate in this economically-active group, the economy is under enormous threat and may soon be devoid of a valuable work force. The country has long been reported to be sitting on a time bomb (Adams & He, 1995 and Campbell, 2005). The impending lack of capacity will also hinder several efforts (for instance, of NGOs, government, CBOs and other charity or socially-responsive organisations) towards providing quality service and care for

those who need it the most and in the sustenance of human development. Without doubt, the demographic level of the country, i.e. its adult structures will be severely altered. A number of studies (Dudwick, 2003; Kelly & Marrengane, 2004 and Ndlovu & Daswa, 2006) have already alerted the country in this regard and have given shocking statistics of grandmother and child-headed households.

The health system is going through severe strain as it has to stretch as wide as possible in order to provide other health services, as the cost of providing a range of services is bound to be skewed towards HIV & AIDS. Other sectors like the education, agriculture and technology sectors are not spared either. Their critical workforce has been reported (see WHO, 2000 and White-Means & Chang, 1994) to be dwindling while at the same time witnessing a decreasing number of clients. Also, it has been reported that, learners (especially girl children) are at times forced either to abscond from school completely or irregularly attend school as the need to look after their sick parents or younger siblings becomes more necessary.

The above statistics and discussion demonstrate that the HIV spread in KZN is influenced by sexual behaviour coupled with other socio-economic factors. The Bhambayi study and other studies (Benjamin, 2005; Kelly & Marrengane, 2004; Leclerc-Madlala, 1999 and Tallis, 1997) have found that these elements are part of the reasons; i.e.:

- a. Risky sexual practices such as unprotected sex,
- b. Multiple and at times concurrent partners,
- c. Failure to treat Sexually Transmitted Infections on time,
- d. Obscure and mythical STI treatment-seeking behaviours,
- e. Gender imbalances which usually fall under the cultural banner - where women are denied sexual rights,
- f. Gender-based violence,
- g. Stigma and discrimination, and
- h. Displacement, inappropriate housing, mobility and poverty.

While the value of the above list is important, various other researchers have different views (e.g. Plant, 1990 and UNAIDS, 2004 & 2005), and it should be noted that other modes of transmission do contribute to the high levels of HIV & AIDS, i.e.:

- a. Mother-to-child transmission,
- b. Blood transfusion,
- c. Exposure to blood,
- d. Sports, and
- e. Injection injections.

#### **4.4 General negative impacts of HIV & AIDS on holistic well-being**

The HIV & AIDS status quo, affects efforts and possibilities towards attaining holistic well-being. Holistic well-being is the integration of emotional, mind, spiritual and physical health. A balance of these faculties is important for a person to function at his or her best. If any one of these functions is affected, a person's health gets compromised irrespective of whether or not he or she has HIV & AIDS. For most people who subscribe to African cultural ideals and a way of life, maximum functioning of these faculties include having good relations and constant communication with family ancestors or any other religious deity as well as being in good terms with one's neighbours. Endorsing IKS, the KZN Department of Education's 2007-2011 HIV & AIDS Strategic Document note that in dealing with HIV & AIDS affected households and individuals it is essential to, 'acknowledge and capitalise on the spirit of *ubuntu*, especially in African communities, when driving our interventions'. It is to this end that for this study the *ubuntu*

outlook, an IKS subsidiary concept, is regarded as a crucial element in achieving holistic well-being. *Ubuntu* is a philosophy which constitutes good morals, good behaviour and being considerate of other people's well-being.

Within the context of HIV & AIDS, achieving holistic well-being is hard as challenges associated with the disease affect people's ability actively to seek employment or produce food. This then results in the re-prioritisation of household and other socio-economic tasks, thereby increasing the burden on care-givers' workloads and general ability to look after themselves as well as persons under their care. Household members with food insecurity and diseases typically care and feed their children less because of increased time spent on gathering food, fuel and water or feeling too weak and sick (Bukuluki, *et al.* 2008; HSRC Report, 2004 and UNAIDS Report, 2006).

A number of studies and scholars (e.g. Aggleton, *et al.* 1991; Brookes, *et al.* 2004; Bryant & Kappaz, 2005; and Hlanze, *et al.* 2005), without alluding to the holistic well-being factor, highlight the need for an increase in sound nutritional, clinical and other health related demands for households with persons with HIV & AIDS.

Both care-givers and patients of HIV positive households need:

- Highly-nutritious food to support an already weakened immune system;
- Improved self-esteem; and
- To reinvigorate their souls & spiritual wellness (Denise and Makiwane, 2003) and, in turn, improve the manner in which they interact with their environment.<sup>22</sup>

The statistics clearly demonstrate that it is not only South Africa that is hardest hit by the spread of HIV & AIDS (Whiteside & Sunter, 2000 and UNAIDS, 2005) but the KZN region is the epicentre of the epidemic (UNAIDS, 2008 and Oxfam, 2008). In addition, given the gender stereotypes that stipulate women's unequal participation in household and community care-giving, their health and well-being is seriously threatened. Many studies and literature listed above concur, the impact of HIV & AIDS on socio-economic and general well-being depends on the patient's gender as well as employability status. For example, if a male head or female bread-winner is sick and later dies, available labour is reduced as family members are

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<sup>22</sup> *Systems Thinking* advocates that these elements and their efficiency are essential for a system (family unit) to operate at its best.

expected to take care of her/ him and consequently, less income is generated. People infected with the HIV and those caring for the terminally ill often struggle to fulfil their work commitments and eventually lose their source of income (Budlender, 2002: 17).

#### **4.5 HIV & AIDS impact on affected households: Stigma and discrimination**

The HIV & AIDS-related stigma has been recognised as a key problem that needs to be understood, dealt with and addressed in any intervention seeking to bring about change. Extensive literature on HIV & AIDS stigma indicates the extent of the problem; listing but a few, I can include Campbell, 2005; Dudwick, *et al.*, 2003; Hlanze, *et al.*, 2005; Jackson, 2002; and UNAIDS, 2007.

Even within families, it is not uncommon to find siblings and/or parents being ashamed of their own family member who has been diagnosed and come out as an HIV positive person. Fellow family members have been reported (Campbell, 2005) and presented (South African Public Television *Soul Buddies* drama series) as not wanting their siblings openly to disclose their HIV status, fearing that their home will be stigmatised and in turn

they will be discriminated against by relatives, friends, teachers and schoolmates. A well-known case and one of the earliest cases of stigma happened in Kwa-Mashu, a KZN black township. In December 1998, Gugu Dlamini, a volunteer field worker for the National Association of People Living with HIV & AIDS was beaten to death by neighbours who accused her of bringing shame on their community by publicly revealing that she was HIV positive. Later, saluting such bravery, one of Durban's park was named after her.

Notwithstanding statements by *The AIDS Epidemic Update* (December 2003) that the law supports and can be a powerful tool against stigma and discrimination, instances of discrimination following disclosure of one's HIV positive status are widespread. Advancing recommendations about enforcing the law and the caring ethic as HIV & AIDS impacts on the most vulnerable, cannot be overstated. Stigma has robbed many people of access to treatment and the right to live a healthy, happy life (Campbell, 2005). As further discussed in chapter five, it is evident from this study that it is not only HIV-positive people but families and individuals caring for them that are affected by the stigma and tend to keep their problems secret until it is too late to receive relevant help. The Bhambayi study reveals the sad fact that stigma and discrimination contribute towards the spread of HIV & AIDS and that this continues to discourage disclosure and



acceptance. In a study (Luthuli, 2008: 77) on school-going teenagers, the author links the effects of HIV & AIDS stigma directly to the patriarchal system. It is this connection that leads Turshen (1991:31) to assert that the root of the stigma problem could partly be attributed to women's subordination and the limited opportunities African women have of gaining recognition and independence.

The *AIDS Epidemic Update*, December 2003 and a multi-country IPAS study on HIV positive women (2005) report that people seeking care or counselling may be rejected by the very services that should help them. Subsequently, those living with HIV can be left isolated and deprived of care and support that could lessen the impact of the epidemic. It is to this end that Youle, *et al.* (1988) believe that it is essential that the counsellor has a thorough understanding of the different lifestyles of people who might be affected by HIV infection, avoiding unnecessary moral judgments. A number of studies claim that in KwaZulu-Natal there are reports that people infected with HIV experience harsh repercussions of stigmatisation. Stigma devalues and discredits the affected people resulting in shame and insecurity. According to Burnard (1992:7) 'friends and families respond and react in various ways to the knowledge that one of them is HIV positive or has AIDS'. Not all are supportive and sometimes the person with HIV or AIDS has to face rejection by loved ones. Silver and Caldarola (1989), cited

in Burnard (1992), state that this may be coupled with the fact that facing AIDS can lead to psychological problems and feelings of dispiritedness and meaninglessness. It is to this end that Corbett (1989) says that distress and suffering caused by ill health of loved ones can result in the suffering of the whole family, especially if the sick person is a breadwinner.

What compounds stigmatisation and discrimination against HIV & AIDS infected and affected people is the attitude of treating sex as a taboo. Some scholars (Brookes, *et al.*, 2004; Campbell, 2005 and Pattman & Chege, 2003) contend that in southern Africa, it is, black communities that report such kinds of attitudes. Luthuli (2008), strongly recommends that it is essential for people to talk openly about sex with their children in order to eliminate against HIV & AIDS related stigma.

#### **4.6 Relationship between poverty, gender and HIV & AIDS**

Hagenaars (1986) gives two meanings of poverty; the first being a situation in which the means are not, or hardly sufficient, to live a life that is considered normal in society. In this discussion, however, the poverty variable is linked to other aspects, i.e. HIV & AIDS and gender inequality.

In a 1996 publication of the book entitled *Women, Poverty and Aids: Sex, Drugs and Structural Violence*, Paul Farmer and his colleagues lamented:

(S)cience fails us. Not everyone has access to what we know. No data, thus made available, adequately reflect all that is most important about AIDS. If you restrict your (internet) search by adding “poverty” to “women” and “AIDS”, the computer will inform you that ‘there are no references meeting these specifications.’ (Farmer, *et al.*, 1996: xiv)

Due to this complaint on the dearth of literature, there have been a number of studies linking the variables that Farmer and his colleagues lamented about a decade and a half ago, albeit scholars do so from different angles. A few, are Adams & He, 1995; Bryant & Kappaz, 2005; Kabeer, 1996; Luthuli, 2008; Ntiisa, 2007 and Seabrook, 2003. The proliferation of literature in this regard is an indication that poverty is a social phenomenon that has a significant effect not only on women but on people with HIV & AIDS. From these studies and many others, we learn how those affected and their family members are driven to unacceptable behavioural patterns.

There are painful experiences and hardships that face them and one of its main root causes is poverty. Some experiences are painful e.g. child

prostitution for children as young as eight years old, suicides and HIV disclosure related murders. Like most women, though worst-off, children are particularly vulnerable to HIV & AIDS because they cannot tell men to practice safe sex – let alone that they may not know that there are laws forbidding such kinds of sexual contact. Sadly, sexually exploited children face serious, life-long and life-threatening consequences. They are also more vulnerable to sexually transmitted diseases as their body tissues are more easily damaged. Poverty and urgent need to buy medication for a severe-ill family member has been cited as one of the reasons some children turn to prostitution.

Although debated by some studies such as those of the HSRC (2007), according to a KZN *Metro Beat Magazine*, March (2005: 20), some of the teenagers fall pregnant deliberately as a way of getting the state's child-care grants. They hope that the money will help them achieve independence and improve their standard of living in some contexts where a parent that had been a bread-winner dies or is severely ill. Findings of the UNAIDS Report (1999) on girls and HIV & AIDS in southern Africa reflect that gender inequality fuels infection because many girls cannot negotiate safer sex or turn down unwanted sex. The report states that HIV & AIDS deepens and exacerbates girl-children and women's poverty, and inequality. In addition, it reports that it burdens women and girls with care

responsibilities, and at times takes them away from school and productive income-producing activities.

Equally, pointing out the harmful effects of poverty and its link to HIV & AIDS, Osmani (1992) contends that nutrition and poverty are very closely related and many aspects of being poor such as hunger, inadequate health care and the stress and strain of living, means being deprived of full nutritional status. Ultimately, the well-being of those affected gets negatively compromised. Osmani asserts that the adverse effects of diet and infectious diseases during early life exert a lasting influence on subsequent development.

Commenting on people living a poor, harsh and short existence without prospects for the future, Christie-Dever (1996) says the risk of HIV & AIDS infection matters little, as it is merely an additional threat to their lives. Poverty may thus make people make hard choices as well as engage in unprotected sex as their only way of entertainment because they cannot afford any other form of leisure. It is to this end that Bettie (2003) argues that teenage pregnancy does not cause poverty but vice versa; girls who become pregnant early and, especially those who go ahead and give birth more often than not, start-off poor. Although it instigated a lot of debate

and unease, the former President of South Africa, Mr. Thabo Mbeki's speech on National Women's Day, 09 August 2004 made a crucial point: he said it is actually poverty that kills people more than the AIDS virus. If you are poor you get forced to make unpleasant choices and you may not be able to afford to buy healthy food and effective immune-system boosters necessary to maximise your general well-being.

Of note, poverty is a gender issue. *The South African National Guidelines of Nutrition Report* (2001) states that it is a duty of a woman to provide a patient with a balanced diet but it becomes difficult where there is no money to buy nutritious food. It is a known fact that many social ills such as crime, violence and drug abuse can often be tracked back to the dehumanising effect of prolonged poverty and unemployment. According to the *South African Cities; HIV & AIDS Challenges and Responses* (2004), poverty and gender discrimination often combine to deny access to drug services that can effectively treat HIV & AIDS; and poverty also limits access to services, appropriate housing and sufficient nutrition. The growth of informal settlements, as is the case with Bhambayi, provides a favourable environment for the spread of diseases including HIV & AIDS and for making it extremely hard to deal with.

Manchester (2004) holds that people with HIV are often trapped in cycles of poverty as their income diminishes and their day-to-day expenses rise. In addition, Manchester asserts that poverty is exacerbated in instances where women who have been divorced or abandoned due to HIV, are in turn left homeless with no proper way of caring for themselves or their children.

Notwithstanding Wilkinson's (1998) point that, infections remain the most common causes of death in poorer countries, even with families that do not start off poor, ill-health infections may lead to poverty. Corbett (1989) holds that sickness does lead to the further impoverishment of already resource-poor households which may be difficult to reverse. Such families may be forced to take private medical care and finance this through a combination of taking out loans at high interest loan rates. Corbett says some families decide that one way of coping with the sickness is simply not to seek treatment where this might jeopardize the economic viability of the household – which then leads to further compromise on their well-being.

According to Adams and He (1995), the overlap between poverty, defined on the basis of income, and poverty defined by expenditure, is poor. In addition to analysing changes in the income of the poor, any analysis of poverty should be concerned with pinpointing the determinants of poverty.

Such an analysis promises to have clear policy implications as government officials and other donors seek to design programmes that address the root causes of poverty. See the recommendations listed in Chapter 6 of the dissertation). Policy makers concerned with the poor should devise programmes to meet considerable dependence of the rural poor and peri-urban (e.g. those living in informal settlements like Bhambayi) on sources of income. For White and Killick (2001), the poor are more prone to illnesses, less-educated and have limited access to basic infrastructure than their counterparts. Subsequently, the reality is that in poor families a poverty trap is created in which the children of the poor are denied access to education by the need to feed the family. To a large extent such denials are structural, i.e. socio-economic systems create and promote the status quo. Seabrooke (2003) says it is thus important to distinguish between poverty and inequality. Whilst poverty measures a state of complete want, on the other hand inequality is an indicator of social injustice. Poverty may be reduced while inequality increases hence the need to have the kinds of analyses like *Systems Thinking* as well as programmes earmarked to protect the poor from further poverty and inequality.

Often, poor people do not and cannot speak for themselves. Seabrooke (2003) says they are forced into silence for the voice of the poor asks for security, sufficiency and an assurance that they will be granted enough for



their needs, not in abundance and luxury, but in peace and an absence of wants. According to Schoub (2000), the most fundamental ethical challenge of all is that of the inequality and unequal distribution of health care resources. For communities like Bhambayi this is a hard-core reality. In KZN, as statistics in the above discussion indicates, HIV & AIDS has caused devastation and is every bit the result of poverty, social upheaval and uncontrolled urbanisation due to lack of development and employment in South Africa's rural areas.

This section of chapter four demonstrates how burdened women are, and how poverty and AIDS lead to numerous deaths which, in turn, worsen their poverty levels and make it impossible to attain holistic well-being. This discussion shows how the epidemic strikes females more, and in the informal settlements like Bhambayi they are the hardest hit by the epidemic. The poor conditions under which they live is the main factor relating to their poverty. For instance, care-givers, who are in most cases women, are expected to make sure that nutrition is adequate in order to limit the speed in the advancement of the disease (Baro and Deubel, 2006). The reality and experiences, as encountered in the Bhambayi community, is that poverty levels render this ideal impossible. In most informal settlement households it is also women who carry out the management of household chores including the distribution of resources.

Anxiety and worry about food can also be a problem even when you are not sick, hence a statement by Luthuli, (2008: 59) that; 'Womanhood in this era of HIV & AIDS is a very difficult task since caring responsibilities are a burden thrust upon women'. Given all forms of discrimination and exclusion, poverty is just another factor that adds to women's burdens.

#### **4.7 Gendered socio-cultural expectations associated with care-giving and HIV & AIDS**

This section explores the socio-cultural expectations associated with home-based care-giving. These expectations are in some way gendered, as relatively, more is stipulated for one gender. Although it is essential to acknowledge and appreciate the good work done by both genders, a number of studies (e.g. Frydenberg, 1991 and Uys, 2001) are in agreement that much of the home-based care is expected and indeed provided by the female folk. At a *Researchers' Forum* at the University of KwaZulu-Natal, Medical School (30 June, 2005), the then Anglican Bishop Njongonkulu Ndungane, rightly put a focus on the fact that within a HIV & AIDS context, as in many other '*labour of love contexts*,' 'women's work is invisible'.

In essence, a woman works from sunrise to sunset with very few people, if any, appreciating her efforts. Feminist scholars and women's rights

advocates (e.g. Brody, 1992; Mills, 1996 and Wollstonecraft, 1996) have, since the early 1960s decried this status quo; (that women work double shifts, i.e. whilst they are employed, they also continue with household chores including caring for family members' physical and emotional needs). A woman is a career woman at a workplace, a mother of her children, a wife to her husband and a daughter-in-law to the extended family (Muthuki, 2005). Magwaza (2009), concurring with Muthuki states that a woman is expected to satisfy all these roles and more. In a context challenged by HIV & AIDS, she raises she raises her children and other people's; clearly her role is onerous. Bettie (2003) thus urges that ignoring women's experiences results in women routinely being invisible and subsequently subjected to strains that may affect their own well-being.

It is such this status quo for women that lead Aggleton *et al.* (1991) to submit that women are most likely to take up the caring roles within the domestic context and become involved the caring roles in the face of HIV & AIDS. Subsequently, Aggleton describes women as 'copers', managing their multiple roles efficiently, and a large number of them as compassionate carers take on additional role. In the same vein as Aggleton, Taylor and Field (2003) correctly note that women are more likely to be the sole 'carers' who spend many hours caring and receive less outside help with

their caring roles. 'Carers' often experience a heavy round of daily tasks, with a reduction in their social lives and increased social isolation.

Although many communities expect women to attend to caring duties, it is unfair to expect women to provide free caring services for HIV & AIDS patients due to unique burdensome challenges associated with the disease. Citing Sims and Moss, Luthuli (2008) argues that taking care and providing support for patients with AIDS requires skill and awareness of the unique needs of such individuals. She says these include the need to feel safe, to be given refuge, to be comforted, and the need to belong. It is time to examine many of our attitudes towards the terminal care of HIV & AIDS patients. Women are also expected to provide emotional and physical care which men cannot and are often not expected to provide, if tasked with similar caring duties. As is the case in the Bhambayi study, some women do not even have proper homes, yet they are expected to provide a sanitary environment. Following a Durban-based study on mothers of different races, Magwaza (2003) says that all these duties and physical contact with children are expectations imposed on mothers rather than fathers. Decrying this status quo she notes that women who choose to leave children are understood to have elevated their own needs and desires above those of their children. These women are made to feel guilty for

leaving children if something has gone wrong with their husbands, family members or the community.

For most unmarried, single and teenage mothers, McRobbie (2000) holds that there is an added disadvantage as these mothers fall into a stigmatized category. Most of them, especially teenagers, as Luthuli (2008) notes, have no access to decent well-paid jobs and they are forced to depend on the welfare grants which are hard to obtain due to the complex South African system that requires tons of documentation and validation. Single parenthood means that financial dependency, which had traditionally been men's responsibility, shifts from the male partner to the state.

Although these demands on women are enforced by the status quo, there are a number of other limitations placed on women that are related to their culture. Wanting to be accepted and to belong, women find that they have to give in to the cultural stipulations that limit their behaviour. Conforming to the predominant values and norms stipulated by culture is not a choice but a coerced behavioural pattern. According to White and Killick (2001), it is important to state that women face constraints that derive from cultural attitudes and religious values that give women low status in society and relegate their work and needs to second place.

## **4.8 Chapter summary**

Chapter four provides a broad context for the HIV & AIDS which provides information and a framework within which the Bhambayi study ought to be understood. It presents statistical information on the prevalence, age, gender, nationality (South African) as well as provincial (KZN) disaggregated population demographics and HIV & AIDS data. The chapter also presents analytical discussions, with a specific focus on how South African society at large and the African Zulu communities stereotype people infected and affected by HIV & AIDS. In addition, the chapter highlights gender imbalances that exist in societies which are believed to have a negative impact on the health and general holistic well-being of the affected people. The discussion points of this chapter serve as a basis for the analyses I delve into in chapter five.

# CHAPTER FIVE

## Data presentation and analysis

### 5.1 Overview and contextualisation of data

This chapter discusses understandings and intersections between collected data from the Bhambayi case study and the various chosen lines of analyses. The soft *Systems Thinking* approach to collecting data is the one mainly used in this analysis. Other theoretical principles (see Chapter 2 of the dissertation) are used to further contextualise the case study. The participants' perceptions and understandings of their experiences are combined and are applied in a bigger social world context within which the study's participants find themselves, i.e. belief systems, values, perceptions of their community. Vaines, 1988 & 1997 holds that it is crucial to have this kind of an understanding as it serves as impressions that may get left behind by interventionists or other interested parties. They are regarded as predominant interpretations gleaned from the research (Vaines, 1997). To

contextualize findings and perceptions associated with this research, an overview of both the case study and analysis is presented.

The discussion of this chapter intends to explore the realities of families affected by HIV & AIDS. The premise of the study is that their voices are hardly ever heard or are consistently left unheard in academic literature, as well as decision-making forums that directly affect their lives. It is necessary to bring these realities to the fore as concerns and needs of families affected by HIV & AIDS differ from those of families affected by other kinds of diseases or families living under better socio-economic circumstances. The *Systems Principles* are mainly used as a tool to look at the families' knowledge and awareness of rights and issues that concern them. Through this tool we also analyse the families' experiences as well as the challenges they face.

There is also a brief discussion (linking it to the discussion of the previous chapter 4, and the next chapter, 5) about dealings with and attitudes of service providers and community members. It is hoped that findings on the families' experiences can then be fed into policy making forums at local and



national level through efforts to source out the voices of other HIV & AIDS affected families.

The narration of this chapter also provides a brief description of the understandings that emerged from the case studies and their significance within the research areas of family, HIV & AIDS, coping strategies, wellness, and Indigenous Knowledge Systems.

This Bhambayi family study sought to explore these questions:

- What issues affect the holistic well-being of persons living with HIV & AIDS?
- How and what do the affected families regard and value 'family'?
- What coping strategies exist for care-givers?

Before delving into the Bhambayi data analyses, a discussion on what the families generally hold as an understanding of 'family', and what affects it, follows. Table 5.1 provides an overview of the Bhambayi participants' perceptions and meanings of family from the experiences shared.

Fig. 5.1 Synopsis of perceptions on family

Question	Perception/ Experience	HIV & AIDS Impact (Analyses)
Who makes up family of the affected?	People who are with them physically and emotionally, people who care for them, regard them as ordinary human beings, and do not always bring facts or insinuations related to HIV & AIDS.	Influences daily life possibly leading to dealing with poverty and health challenges better.
What affects holistic well-being of persons with HIV & AIDS?	Good/ bad treatment, neglect, accusations, inability to access health resources.	Knowing where to turn to in time of need, being accepted.
What brings hope and ability to cope?	Caring family, having a job, security, spiritual connection with ancestors or Jesus Christ.	Spiritual growth, acceptance and comfort have positive effects.
What dismantles hope?	Declining health, lack of close people/ family, poor service providers, poor service.	Ill-health ensues as holistic well-being is affected.

Adapted, source Wong-Wylie, 1997

From the above table it is evident that perceptions play a significant role in people's well-being and in turn make a contribution towards improved health as well as hope for the future. The study found that how individuals term their family and who they regard as family is a major factor in their general well-being. The term 'family' and family members was found to be fluid – not rigid and prescriptive as it is sometimes thought about African indigenous families (Msimang, 1975). The study, concurring with Wong-Wylie (1997)

thus concluded that a 'representative or static definition of 'family' is not important'. Interaction and being cared for by a chosen family member, however, was found to be important and essential in dealing with community prejudices and physical negative impacts of HIV & AIDS. Thus, from the empirical research it was evident that two crucial lines of analyses were significant and appropriate to better understand realities that the Bhambayi families go through;

1. A Soft systems approach that accommodates multi-pronged terms & approaches,<sup>23</sup> and
2. Social constructionist approach.

All the studied families presented striking similarities in their attitudes and responses towards HIV & AIDS. There were overlaps on how/what they regard as a family and on ideals of wellness – which revealed a close relationship between wellness and hope.

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<sup>23</sup> It should be noted that, in essence, *Systems Thinking* from which systems approach emerges came about as a pioneer of an interdisciplinary approach to studying problems. In this dissertation such an approach is employed with other approaches to conceptualise and come to a better grasp of the Bhambayi research situation.

## **5.2 Main participants of the study and presentation of their stories**

In delineating the main research question, this section integrates perspectives and perceptions of the key participants of the study. This is done by, on the one hand, recording their personal stories, and on the other, by employing these stories to respond to the main questions of the study. It is also within this context that related characteristics of *Systems Principles* and other theories are used to further unpack the participants' experiences. Although theoretical and philosophical at surface level, these principles are also found to be sound research writing and analysis approaches. Supporting this assertion and concurring with adopting this kind of an approach, Wong-Wylie (1997:9) says that it is important for a researcher to have a full understanding of and documenting tools for the subjective meanings of family members as a form of the researcher's demonstration of his/her respect for the diversity that exists, even within a community that has similar identity elements and challenges. It is to this end that the dissertation makes concerted efforts to explore and present the actual meanings of the participant's experiences – deriving them largely from the participants themselves.

Hereunder are the stories and voices of six persons representing six families living to and/ or directly affected by HIV & AIDS. As a researcher I could

relate with a number of their story points. The self-reflexivity approach (see 3.2.2) was not only confined to the six participants; I could also reflect on my own motherhood experiences. Given that it is women who are often expected to provide most support and care to AIDS victims and HIV positive people (Akintola, 2004 and Benjamin, 2005), this dissertation presents testimony from one man and five women care-givers. The study did not have any other willing male participant to participate in the study. The conventional African cultural notion and practice demands that first the mothers, then other women rather than any other family member, ought to provide care. In turn, the term 'mother',<sup>24</sup> irrespective of its traditional dictionary definition, has become associated with care-giving. Thus, it is important to understand how, in particular, mothers deal with the challenges of looking after children orphaned by AIDS.

The case study under discussion, taking its cues from the broader Bhambayi community under investigation, refers to all six caregivers, including the male participant, as 'mothers'.

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<sup>24</sup> To a certain degree even the terms "parent" and "parenting" are, within this society, strongly associated with women, in particular the biological mother.

Specifically, this chapter aims to:

- Examine the construction and meaning of the term 'mother';
- Problematise the fact that the extended motherhood concept and practice pose questions to an African traditional understanding of the concept in the 21<sup>st</sup> century;
- Present coping and survival strategies used by the 'mothers' in their mothering practices; and
- Discuss socially-constructed implications and impacts deriving from being HIV & AIDS infected or affected.

### **5.3 Recap on the development and context of the case study**

This mini-study, and, in particular, this chapter emerges from a larger study that focused on the aftermaths of HIV & AIDS in the KwaZulu-Natal Bhambayi (Inanda) community, located in a shack dwelling and informal settlement. The aim of the larger study was to examine and record the participants' voices and ways in which they understand and live within HIV & AIDS circumstances. In the course of the study I observed that the concept 'mother' was employed in a manner that challenges the African traditional understanding of the term thereby forcing a redefinition of the concept. In

the African context the term had come to be accepted as a variable that applies to a woman, her biology and to a certain extent, her age.

The focus of this discussion is purposefully on six of the fifteen participants initially identified and included for in-depth interviews (see chapter 3 for further details on the adopted research trajectory). Common characteristics are presented first, followed by a further explanation about each participant. The participants' ages range from 15 to 90 years. All the interviewees are South Africans and Zulu speakers. As with the rest of the participants excluded from the discussion, the main participants of the study have some points in common: i.e. none graduated from high school, each has chosen not to have a sexual partners, although not one has a formal kind of employment, all have some constant means of 'putting bread on the table' for their families. All the participants care for children between the ages of 3 and 16 years of age and are the main care-givers for the children. On average, each participant cared for three children and was, at the time of the interviews, living with the children in the same abode. The actual names of the participants, as they were promised, are not used in the discussion. I make reference to them either by the use of pseudonyms or by age.

## **Main participants' stories**

**Linda**, a fifteen year-old girl, is the eldest member of her family, which comprises herself and her three year old and eight year old brothers. After the death of her mother, when her youngest brother was only 18 months old, the children briefly stayed with relatives. The relatives live in various parts of KwaZulu-Natal and they stayed with them for periods ranging from 2 weeks to 3 months. She says that they were compelled to return to their mother's Bhambayi shack when she was severely beaten up by relatives following an accusation of stealing some money. Although there have been reports (Ntiisa, 2007 and UNAIDS, 2008) that negative attitudes and insinuations against HIV & AIDS victims are diminishing, there continues to exist anecdotes of people experiencing the effects of stigma. Linda, battling to hold back tears, shared her story:

I know that the false accusations were related to the fact that my mother died of this disease. Often I would be told in the face that all of us are not good enough, will some day rot in jail because of low morals passed on to us by our mother. The discrimination we went through has destroyed relations with our family people. I am back home now and prefer it this way, as I, at our relatives, was treated as a slave or some kind of an unpaid domestic worker. I would be given extra loads of work that I battled with and at times went to bed like a



sick dog. Mh, I vividly recall that, unlike the rest of the kids, we, the three of us would also be restricted in what we could eat.

Prior to taking full responsibility for her siblings she considered suicide, but states that 'being a mother to the boys now gives me a reason to stay alive.' Linda looked at me in disbelief and was rather surprised when I referred to her as a child. During our discussion, she was mostly on her feet ironing her older brother's school uniform. She herself had had to cut short her schooling, mainly to fend for her brothers. She gets some money selling candies and crisps on the street. Although she did not make any reference to her brothers being infected with HIV, their physical states indicated they could be infected with the virus.

**Thembi**, an HIV positive woman, is 28 years old. She looks after three girls, two of whom are of a sister who died of AIDS. They are aged 11 and 13 years respectively. The third child is a three year old whose father has recently passed away. Although she had recovered from recurring bouts of sickness at the time of the interviews, Thembi's health condition made her decide to quit her last job as a shop assistant. She gets some money to sustain her family by cleaning houses of two Indian families that live close

by. As the money is insufficient to cover family expenses, the older girls sell fried fish during school breaks and after school hours. Thembi states: 'As a patient and a parent with no proper income, my life is a challenge. Although our needs outweigh our means, as both father and mother of these children, I must be strong for them, especially when I am not well'. Her outlook on life is positive and she regards herself fortunate that she has some kind of employment and a bit of energy to help the less fortunate by bathing a friend she met at a support group she used to go to. The friend's health is worse than hers. On one of the days that I visited her she seemed sad and reflected:

You just do not know what has been pestering my mind these past few hours ... thinking back about the number of deaths we have had – all the pain we went through with the earlier funerals may be faced again. I may have another child to bury. The little one is very ill. This is too much for me now. I need help. Our struggles are not made any easier by the nurses – their attitude and treatment is enough to keep you away from the clinic for months!

Immediately thereafter she beams with confidence, 'But, whatever I may look like eventually as an AIDS person, I can always project a loving, courageous, decent, and hopeful attitude. I will be fine'.

**Lucky**, a volunteer at the local AIDS hospice is the only male 'mother' amongst the six participants. He is 33 years old and cares for two nine-year old boys, neither of whom is his own. One child is Lucky's nephew, as the child's mother was Lucky's sister who died the week I first met Lucky. The other child, as Lucky puts it, 'was acquired under painful circumstances. At her death bed at the hospice, his mother asked me to adopt him. The death of the two mothers of these children compelled me to take them into my care'.

Although the 33-year-old man has not formally adopted the children, he receives a grant from government on their behalf. He is adamant about his role as a mother for the children. In an assertive manner, somehow speaking on behalf of the children and himself, he says, 'Regardless of our physical condition, there is this courage I have - to project ourselves as positively as I can, and in so doing, challenge us, as well as the world to reflect upon the hope and spirit embodied in a less than perfect body and situation'.

**Dolly**, a 46-year-old woman, mothers five children in total. Two are three year old twins of her daughter whom she strongly suspects died of AIDS, as indicated by the symptoms shown a few weeks before her death. The other three children are her own. She treasures the children as a manifestation of God's love for her. She says: 'As a child, I always wanted to have many children and hoped to become a kindergarten teacher. That dream is somehow realised but with no compensation as it is common to find additional five or six children in my company. They know I like them, they inspire me and I appreciate that, unlike adults, the children do not judge and pass cruel comments about my children'. To support her family Dolly sells fruit and vegetables on the street.

**Zanele** is a 52-year-old woman who has been a widow for twenty-four years. She is essence a foster mother but detests such reference to herself – maintaining it is unZulu and insensitive towards her and her children. Her husband was gunned down by robbers barely four years after they were married. She has decided not to remarry. Zanele and her husband had hoped for a big family. She told me it would have been her 'way of making up for the brothers and sisters I never had and the fact that I spent many years in foster homes'. Their wish, however, did not come to fruition as they

only had two children from the marriage. Without a premeditated plan, her passion for a large family ultimately saw her looking after a minimum of five destitute children each year since her husband's death. This number has now gradually increased as the number of destitute children grows daily because of the HIV and AIDS pandemic. Her home has become a haven, especially for children orphaned by AIDS. At the end of 2008 her home, now regarded as an institution, sheltered 16 children, and boasted two assistants and a part-time security guard. Although Zanele receives a grant from the state and is supported by a number of donors, she refuses to refer to the children under her care as abandoned or orphaned. She emphasises that she was called by God to 'be a mother to the nine girls and seven boys, the big family I once earnestly pleaded with God to give to me.'

**Elsie**, who never got married, is a great-grandmother to the three children she takes care of. When I asked how she copes, given her old age, she sighed; 'I may be a 90-year-old tired horse today, but all my life I have been looking after children, either my own, or the relatives' children and now, my late daughter's. 'These children' (pointing at her great grandchildren in the room)' are the reason I am still alive'. Like Zanele, she speaks of her caregiving as a mothering role. In the years 2003-2005, Elsie says, 'Three people have died from this house, dying of the new disease – that is my

daughter and her two daughters. My great grandchildren could be my ancestors' strategy of filling some gaps in my life, because if I did not have this family I would be on my own, just by myself.' The 'new disease' referred to by Elsie is generally understood as the HIV & AIDS scourge. The three people who died were her daughter and grand-daughters. The three children Elsie cares for are three, nine and ten years old respectively. All live off the meagre pension allowance she receives from the state.

#### **5.4 Discussion and analysis**

The Bhambayi case study demonstrates that poverty, limited or no resources, and societal prejudice against people affected by HIV & AIDS can constrain affected families. The study reflects that gender inequalities and roles' expectations, in addition, can further constrain women's access to care, treatment, support as well as their ability to use treatment, information and advice to improve the quality of their lives. It also recognises that the care, treatment and support needs of HIV & AIDS affected people, specifically living in circumstances as that of Bhambayi, are different. It thus becomes essential to employ a multifaceted tool like the *Systems Thinking* approach to gain a better understanding of a studied area.

One of the reasons for adopting a *Systems Analysis* approach in this study was to generate information that would be useful for gender analysis and in turn, provide essential guidelines for the development of gender-sensitive interventions. A brief discussion of such interventions is discussed in the dissertation, see Chapter 6. They would be useful for donors and intervention practitioners to implement, in order to advance enhancement of the holistic well-being of the Bhambayi and other similarly affected, family members. Concurring with Sokoya (2003) who takes cues from a feminist poststructuralist analyst, Weedon, (1987), this study acknowledges that in order 'to work towards egalitarian feminist goals, gender analysis has to be applied to both men and women so as to understand men's participation in daily life, gender stereotyping, and the enduring puzzle of why women put up with male domination' (Sokoya, 2004:237).

#### **5.4.1 Fluidity of the concept and practice of 'motherhood'**

The term 'mother,' *umama*, sparks a dynamic image amongst people, depending on who is using or receiving the term. In the African context the term is likely to be associated with a woman, but it also comes with assumptions that the woman has given birth to a child. Due to the awe associated with the life-giving miracle, a mature woman will be respectfully addressed as *Mama*. Other than the biological understanding of the term, its

next close use includes: a woman of your mother's age, a mother's sister, a mother-in-law, and a church minister's wife. Also, providers of nurturing services, such as care-givers, are referred to as *(o)mama*. Sara Ruddick, in her book *Maternal Thinking* (1989) proposes that the act of mothering should be seen as affording care or nurture to children, a role she argues is independent of biological maternity and can be carried out by both men and women. This assertion has also been recently supported by other scholars, such as Doucet (2006), and constitutes a strong argument in favour of gay couples adopting children. In an African context such a definition of mothering would cause a stir.

In the case of this study, however, I maintain that the role of the six main 'mothers' of the study supports Ruddick's standpoint, as it includes a child as well as a man assuming a mother's role. In most HIV & AIDS literature the 15-year-old mother, one of the participants in the study, would be referred to as a child-household head, and not necessarily as a mother; and yet, she does not only perform the duties expected of a mother, but categorically calls herself a mother. As pointed out earlier, the man participating in this study also regards himself as a mother. I therefore submit that this study exposes the widening concept of 'mother' from an African point of view, and challenges it also from the perspective of general motherhood research.



The six mothers presented in this study have an attachment to the responsibility of mothering both in a practical and a symbolic sense. For them it is not only the role of providing primary care for the children that is significant, but also the symbolic meaning of being there as a mother for each one of them. Calling themselves 'mothers' is a significant reason and expression of being proud of duty. All the mothers, in varied ways, regard their status as either the ancestors' or God's way of making up to them for biological parenting that is either overdue or unlikely to happen.

Five of the six participants defined their mother status in non-traditional terms, thereby altering the limited understanding of motherhood. Fascinatingly, none of the definitions conform to the common African concept of motherhood. The 15 year-old girl and the male participant regarded the children they care for as gifts from God and in lieu of the fact that they shall never have children of their own. Sadly, both stated that they were certain they would not get involved in any romantic relationship ever in their lives, as they fear contracting the HI virus. The 28-year-old HIV positive mother who cares for three HIV negative children, her own and of her late sister's, considers she is lucky to be a mother of three. She vows she does not want to have anything to do with men, as her previous

boyfriend not only passed on the virus to her, but dumped her when he learnt she was pregnant and HIV positive.

Evidently, HIV & AIDS impacts on sexual and reproductive rights (knowledge and acting upon it)<sup>25</sup> – as the care-giver's sexual and reproductive health needs as well as their different needs that they may currently have or in the future, are compromised. despite some difficult choices they make, however, the Bhambayi care-givers, like all human beings do have sexual rights, i.e. 'the right to treatment for sexual health problems, the right to have consensual sexual relationships, and the right to choose if, how and where and with whom these are carried out, the right to protected sex, the right to pleasurable sex, the right to bodily integrity and freedom from sexual intimidation, coercion or force'.<sup>26</sup> Whatever the choices they make they need to be made aware of these rights. See a discussion in Chapter six.

From the above testimonies it is obvious that the HIV & AIDS context is largely responsible for the significant shift in the understanding of the concept of motherhood within the African context. It can be argued that, for

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<sup>25</sup> See Hunt (2007).

<sup>26</sup> Refer to "General Comment 14, E/C. 12/ 200/4 (11 August 2000)" which was adopted by the UN Committee on Economics, Social and Cultural Rights, in association with the WHO and other organisations, on rights to medical care.

these mothers, the attitude and self-naming they adopt forms part of their coping strategy.

This study maintains that the practice of mothering that the mothers construct and execute is informed by a number of factors. Among others: Zulu cultural constructs, an individual symbolic significance attached to the mothering, irrespective of orthodox values held within their community, the ideals of *ubuntu* (humanity),<sup>27</sup> and a means of self-healing.

It could be argued that the traditional Zulu concept and practice of mothering lends itself to an extended usage. In fact, in a polygamous household, all father's wives were 'mothers' to all the children, although there was a difference between the biological mother and the other 'mothers'. On the other hand, the mother's brother, *umalume* (uncle) was understood as a male mother and had a very special relationship and responsibility for his sister's children. Orphans were readily adopted into the families of their father's brothers, or, in their absence, and under different terms, by the mother's brothers. Such traditional practices point to an extended understanding of 'motherhood,' not based on the biological factors

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<sup>27</sup> An IKS notion.

of being a woman and having given birth, but based on an emphasis on the nurturing and caring functions. In modern societies, however, the ties that linked the traditional extended families have become loose, and the 'motherhood' concept has become more restricted.

Unlike most residents of the Bhambayi village, four of the six mothers were found to distinguish themselves in caring for other people besides their own children. Other than their main mothering care duties, they mentioned that they regularly provided care for other people as well, that is, AIDS patients and the elderly.

#### **5.4.2 Importance of grandmothering in an HIV/AIDS context**

What has been held by most communities for many years is that grandparents have a special significance in their grandchildren's lives, with grandmothers having more influence. Data presented in the Bhambayi case study concurs with some care-giving researchers' assertions (Betram, 1981 and Bowers & Myers, 1999), who note that since the late 1980s there has been a dramatic increase in the number of grandmothers taking up the role of a primary care-giver for their grandchildren and great-grandchildren. The study further confirms that it is more common for grandmothers than

grandfathers to participate in parental activities. In most communities of southern Africa, the grandmother's age or lack of employment does not negatively affect nor limit her parental involvement. This study indicates that grandmotherhood, like motherhood, is a construct. In the Bhambayi case study, however, mothers (participants of the study) assume the role, and regard or name themselves mothers. The demands placed on the grandmothers are enormous, and differentially difficult compared to the demands placed on her male counterpart.

The Bhambayi grandmothers are forced to evolve and adapt due to the HIV & AIDS challenges they face. de la Porte and Meyiwa (forthcoming) state that about four to five decades ago co-residence among grandparents and grandchildren used to be a norm in a number of communities, however, this phenomenon later changed due to urbanisation, industrialisation - and the scourge of AIDS, from which many parents die. The impact of HIV & AIDS on grandmothers is insurmountable, as many grandmothers raise their grandchildren as a result of an AIDS related death of their children. In these contexts, as is the case in the Bhambayi study, grand-mothering is transformed into mothering. de la Porte and Meyiwa further note that in South Africa, for instance, the disease is at times referred to as the 'grandmothers' disease' as many grandmothers in impoverished

communities are largely responsible for both nursing their sick and dying children as well as being actively involved in co-parenting and raising their orphaned grandchildren.

#### **5.4.3 HIV & AIDS and foster mothers**

Foster mothering is one of the realities that HIV & AIDS imposes on communities. In the case of Bhambayi one of the main participants, though a foster mother by definition, chooses to regard herself as a mother of the children under her care. The participant is in essence a foster mother as she is a woman who is not the biological mother of a child and raises a child outside of the biological mother-child dyad. Under normal circumstances, children are formally placed in the custody of a foster mother by the state authority, or alternatively, the process may be voluntary in nature – as is the case with Zanele of Bhambayi. Similarly, studies (Jones, 1992 and Walmsely, 2008) indicate that the most common motives for becoming a foster mother include maternal desire, often a result of not being able to conceive, the will to help and provide a safe haven for children in need, and a strong identification with deprived children. In such instances, the foster mother has usually experienced resilience and developed coping strategies. Refer to the above discussion and story on Zanele, a typical foster mother. She provides a home for children needing an abode following their parents’

AIDS-related deaths. Within HIV & AIDS contexts, the number of children being absorbed into households on a more permanent basis has increased dramatically, placing tremendous social and economic strain on households.

Some studies assert that the cultural norm of 'purposeful' voluntary fostering has been replaced by 'crisis fostering' as traditional voluntary care-givers succumb to the effects of the disease.

#### **5.4.4 Stereotypes associated with HIV & AIDS pandemic**

This section briefly examines the impact of language,<sup>28</sup> peoples' perceptions and attitudes on HIV & AIDS, and how the stereotypical discourse reveals people's perspectives and in turn leads to unwelcome behaviour towards affected family members at a community level. In particular, I examine the stigmatising process relating to gender stereotypes and discrimination of people affected by HIV & AIDS. van de Wouwer (2005) is of the opinion that people's use of words often demonstrates that language is not neutral in its use but is intentionally marked with negative impacts. He submits that, this is evident in the numerous HIV & AIDS misconceptions encountered in gender stereotypes which considerably influence people's stigmatising attitudes and discriminatory behaviour towards those infected and affected - most of the victims being women.

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<sup>28</sup> Words used in conversation with or without affected parties.

Examining the stories and experiences that the participants of the Bhambayi case study have gone through, it is apparent that gender stereotyping compromises sexual health. As observed with the sexual choices made by some participants of the study, it is a fact that, as a sexual health website ([www.fhi.org/en/RH/Pubs/Network](http://www.fhi.org/en/RH/Pubs/Network)) maintains, expectations about what it means to be a man or a woman, who are an integral part of most children's socialization, leave many adults ill-prepared to enjoy their sexuality or to protect their health – thus playing into societal stereotypes. It is to this end that some experts (e.g. Butler, 1999; Morrell & Ouzgane, 2006 and Morrell & Ritcher, 2005) maintain that challenging traditional views of masculinity and femininity is essential to promoting sexual health and to fostering safer sexual behaviour.

Gender stereotyping is are linked to violence and sexual exploitation as discussed earlier in the dissertation. The stereotyping, as demonstrated in the Bhambayi case study, suggests violence may restrict access to health information, hinder communication, and encourage risky behaviour among women and men. Eventually, the stereotyping may increase vulnerability to sexual health threats. Aligned to the sexual stereotyping are gender role stereotypes. As many scholars point out (e.g. Squires, 2000 and Squires,



1998), from an early age, both men and women are socialised to believe that gender roles are 'natural,' and this, in turn, contributes to beliefs that risky sexual behaviour is unavoidable. One male interviewee of about 30 years old (not one of the main participants of the study) stated;

Everyone engages in sex and many people have more than one partner – so we are all destined to die from AIDS. Actually we will all die one day, so what is really the big deal? Condom or no condom, we will all die some day.

The Bhambayi care-givers' stories and their never-ending 'motherhood' roles are an indication that like many societies, the Zulu culture prepares girls to be 'good' mothers or wives by socialising them to serve unconditionally even at their own expense. Families, relatives, teachers, and peers reinforce the assumption that women and/or mothers are 'servants'. In addition, women's low social and economic status (Harris, 1995 and Ngcongco, 1993) throughout much of the world poses serious threats to their sexual health. Inferring from the above interviewee's assertions, the power imbalance between men and women makes it impossible for women to refuse unwanted or unprotected sex or to negotiate condom use against a male partner's wishes.

#### **5.4.5 Violence against HIV & AIDS affected families**

The Bhambayi study demonstrates that violence against the families is a reality. Violence against women and girls (VWA), however, is rife. Violence can take many different forms including verbal, physical, sexual, emotional, financial, and psychological violence. It can also take the form of fear of any of the above. This was evident in the testimonies of Linda and Thembi. The use of the term VAW should be understood to include the following types of violence or fear of these, some of which featured in the participants' stories, i.e. rape; incest; statutory rape (sexual intercourse with children or young people below the legal age of consent), marital rape, refusal to use available protective technologies to safeguard against (re)infection or transmission of STIs (including HIV), domestic violence' battery and assault' verbal violence or bullying such as cursing and use of swear words and derogatory terms, sexual violence including sexual intimidation or threats, stigma and discrimination' refusal of medical examination or treatment, withdrawal of financial support, abandonment, community violence (e.g. setting fire to someone's house), violation of human rights, being deprived of access to and ownership of property after the death of spouse (Beijing Platform of Action 1995).

#### **5.4.6 Survival and coping strategies**

A baffling common trait of all six mothers is that they do not have sexual or romantic partners. With the exception of the 15 year-old participant, the reason offered as an explanation for the decision was the children's health, care and welfare. The mothers felt good and grateful for their 'unattached romantic status', which they say: offer some guarantee of a disease-free life and thus surety to protect the children's health. Their choice cannot be understood outside a socially-constructed expectation that mothers should 'sacrifice their own life in many respects for the children's benefit'. This is a consequence of the traditional tenet that giving, preserving and nurturing life is the highest human (often expected of women) attainment. On the other hand, such a self-sacrificial could also be understood as a coping strategy.

There is no doubt that mothering under the HIV & AIDS circumstances is a challenge. It was significant to note that three of the five mothers cited the 15 year-old girl-mother as their inspiration, as she single-handedly looks after two children. She was referred to as a good model and one of the reasons that the mothers try to be strong during hard times.

Strength to persevere in caring for the children, especially without the support of formal employment, was drawn from a spiritual source. Religion has been reported to play a significant part in this instance.<sup>29</sup> In particular, guidance from the Christian religion and the ancestors were cited as sources of strength. Four mothers mentioned that one of the dominant demands in their prayers was to live long enough to see the fulfilment of God's or the ancestors' plan for the children. Aware of the high rate of death in areas of HIV prevalence, all the mothers wished for a long life, out of concern for the children. It was found that the wish was also prompted by the sad realisation that few members of the family<sup>30</sup> were interested in caring for the children. Also, all the participants had some affiliation to a support group, whether formal or informal. This was identified as necessary as the need to talk about one's situation eases the difficulty of facing HIV & AIDS factors in their lives.

A common feature among all the mothers was that, although they were not in formal employment, they were all involved in some trade activity aimed at complementing their main source of income. All the participants, except the youngest and oldest mothers, were in regular contract employment. In addition to this kind of employment, most mothers were involved in some

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<sup>29</sup> Philippe Denis and Nokhaya Makiwane (2003) make reference to this fact following a study on coping strategies of some South African families directly affected by HIV/Aids.

<sup>30</sup> In the African context, the term 'family' refers to an extended family.

kind of income-generating activity: selling anything, from loose single cigarettes to fruit and vegetables, or candies, crisps and fried fish. The needs of the growing children in their care were cited as reasons for such economic enterprises.

As another form of coping with HIV & AIDS, it was apparent that the families (consciously or not) had started challenge some Zulu traditional worldviews. A number of traditional cultural Zulu values are now challenged by these families. The concept of what constitutes a family, that is, a married heterosexual pair in a stable relationship, with the man being the head of the household, is strongly questioned. Magwaza (2003), reporting on an African Zulu mothering practice, notes that the mothering duty is ideally considered a communally-shared practice, probably developing from traditional polygamous settings where each wife was also the mother of all the children in the household. In a Zulu traditional setting neighbourhood mothers, mothers' sisters and grandmothers would often be within reach to offer help.

In the Bhambayi study, however, it was found that for all the mothers in the study this ideal option was deliberately shunned, indicating an altered

experience of motherhood. On asking about communal mothering, all the mothers were adamant that they did not favour the practice. Instead, there is a conscious support network amongst three of the mothers in the study. They maintain their support group is a better option, and has worked well for them. It transpired that this decision was made out of fear that, should the network be extended to include mothers with no experience of AIDS deaths, their families might be hurt. Stigma and insensitivity towards families that have suffered AIDS deaths continues to be a concern within South African society.

The care-givers cited many reasons as their means of coping with their HIV & AIDS circumstances; for instance, Zanele, the woman with 16 children at a 'funded institution', is a widow. She regards the children as a great gift from both God and her dead husband's ancestors; a token for the children she could have had, had her husband lived longer. In the same vein, the 90-year-old great-grandmother also stated:

I had to have these boys as my own, as their mother. It is good they are well and healthy. They will carry the family name to the next generation. They are living proof that I had boy children.

## **5.5 Application of *Systems Principles* to the case study**

This section uses the terms *Systems Principles* or *Systems Thinking* to refer to all the theories used as the framework of the study. See the discussion of (Chapter 2 on the theories). The framework incorporates the classical systems' principles, feminist principles and self-reflexivity. (See Chapter 3 of the dissertation). The framework also encourages, grounded theory, social constructivist theory as well as principles of the indigenous knowledge systems approach. The framework has been expanded as a meaningful conceptual outline that assisted to formulate and interpret ideas and data at various stages of the investigation. I maintain that this is not only a valuable framework for understanding the Bhambayi case study but it is a meaningful perspective to influence change for the benefit of the families.

*Systems Principles* is an approach and perspective that embraces diversity, thus accommodating multiple views and approaches to the research problem. In addition, it is an appropriate outlook to guide individuals and organisations to be intentional about their impact on the lives of family members who are living with HIV & AIDS. Many assumptions of *Systems Principles* are applicable to this endeavour, as for example, an essential assumption is that humans are interdependently connected to their surrounding environments (Bubolz and Sontag, 1993; Midgeley, 2000). This

holistic perspective, in which to regard the families, acknowledges all contexts including the socio-economic and cultural milieu (Magwaza, *et al.* 2006); a person with HIV & AIDS may be situated within (Bubolz & Sontag, 1993). Employing a systems approach to interactions and interventions with persons affected by HIV & AIDS sensitises external people to always consider the context affecting the affected people and thus contribute towards achieving holistic well-being.

The systems approach guides people to consider cultural, societal, community, and personal experiences of the affected families and individuals and encourages them to consider what may be important to the individual to optimize awareness of how an interaction may in turn affect their survival and bring about hope (Wong-Willie, 1997 and Ntiisa, 2007). Another fundamental hypothesis of such a multidisciplinary approach is that people have the ability to promote change (Connell, 2005), emancipate victims of oppression through action (Wollstonecraft, 1996 and Tallies, 1997) and advocate for quality of human life conditions (Mills, 1996 and Mulugeta, 2008). Clearly, a systems approach outlook advocates that caring for people holistically is an important value. It is the thesis of this research - that within such an optimistic and compassionate view, it is possible for all stakeholders to work together towards not only considering the environments of those



individuals living with HIV & AIDS, but also to work on improving their environment to create an atmosphere that is conducive to fostering hope, and in turn, prolong the life of those directly affected. In addition, with the attitude and an approach of compassion, consultation and partnership, the *Systems Thinking* approach would stimulate government and non-governmental and community originations, family members, and all persons to work together in pursuit of the common goal of engendering hope for those facing this devastating illness.

The *Systems Thinking* perspective also encourages family members to be self-reflective (and thus takes on board tools of the self-reflexivity approach). The work of Dahlbom & Mathiassen 1993; Littlejohn (1999) and Sullivan (2002) suggest and provide evidence that thinking critically about ourselves connects our story with fellow human beings, their stories and the natural environment around us. Concurring, Wong-Wylie (1997) asserts that self-reflectiveness is important for persons to gain an awareness of their own experiences, environments, and hope, and thus, have optimal awareness of others.

As such, the systems approach assists, within intervention programmes involving beneficiaries and officials, in building a balanced perspective in which to regard oneself and others – and subsequently leads to a better transformed life (Albrow, 1999 and Flood, 1999) for those affected by HIV & AIDS. It also promotes the constant consideration of meaningful relationships. Henceforth, those who are affected are involved and encouraged, (through this principle of *Systems Thinking*), to consistently examine their own assumptions, inferences, feelings and experiences; this can impact on their survival strategies in a more meaningful way.

This dissertation demonstrates that classical *Systems Thinking*, which is multidisciplinary in its intent, and accommodation of other diverse problem-solving techniques, is not only a valuable framework for the affected family members but can also be employed by researchers to guide future research endeavours within the disciplines of family, community relationships, HIV & AIDS, hope, and cultural interactions.

Employing, the social constructivist approach specifically, systems approach can be considered as a conceptualisation seeking to interpret a community's process of 'selecting, ordering, and organizing information relevant to ones

own experiences' (Wong-Wylie, 1997:90) and in turn explain as well as understand beliefs systems and biases found within a community. (See Chapter 4 of the dissertation).

*Systems Thinking* is valuable as a comprehensive approach to guide investigations into various interactions of families affected by HIV & AIDS, and thus it provides an increased understanding of the affected families and possibilities of making a positive impact on their lives. Taking cues from the self-reflexivity approach, and given the compassionate and optimistic approach of *System Thinking*, subjectiveness involved in perceiving and dealing with families creates better opportunities for developing social supports and resources that can help foster hope, coping and subsequently, holistic well-being. (See Chapter six).

In using the social constructionist perspective, I argue that mothering choices indicate society's expectations of a mother; i.e. that she is expected to give up everything in the interest of her children (sometimes referred to as 'bundles of joy'. Such an expectation fails to take into cognisance the mother's personal beliefs and preferences. As critically discussed in (Chapter 2 above, it is common to find women, rather than men – opting for such

personal sacrifices that may extend to completely towards abandoning one's life in favour of the children's well-being. Although the social upbringing and cultural backgrounds may be blamed for this, the social constructionist theory contends that those who 'abandon their lives' (as it was found to be the case with some Bhambayi mothers) play a significant role in what happens in their lives. It is to this end that the constructionist perspective endorses that 'individuals are meaning constructors and the significance of those meanings must be understood as contextually embedded' (Albrow, 1999:124).

It was interesting to find that in the Bhambayi study, notwithstanding the fact that five of the six mothers did not give birth to the children they look after, they term their role as mothers and sternly commit to the children – in a manner that infers that they 'abandon their lives'. The statements and parental duties of the 'mothers', the main participants of this study, indicate a will to sacrifice and demonstrate special significance each mother has for the children, be they a biological mother, grandmother, foster mother or a great-grandmother or even a male guardian.

The Indigenous Knowledge Systems' perspective, especially with reference to the *ubuntu*<sup>31</sup> (humanity) principles and philosophy, was also used to conceptually analyse the collected data. All mothers cite the act of giving their life and energy to the task of mothering as an expression of holistic caring. This is a kind of caring that embodies care for the health, emotions and general well-being of a person - a fundamental concept of the principle of *ubuntu*. Besides using the social constructionist and *ubuntu* framework, the grounded theory qualitative methods were utilised for analytical purposes. In particular, it is the underpinnings of Glaser and Strauss' (1967) grounded theory principles, which were later developed by Strauss & Corbin (1994) that were employed for this purpose. The techniques of this theory are essential in knowledge production and exploratory studies. I regard this study as falling within the ambits of such studies. The theory maintains that research focus should be on the participants' main problems and the manner in which they try to solve them, rather than on preformed hypotheses. At the centre of this approach is the act of 'being sensitive,' that is, being acutely aware of the participants' perceptions and choices.

The concept and practice of mothering, family, and associated challenges within a HIV & AIDS context, explored through a study that employs

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<sup>31</sup> This is a philosophy that is largely based on the need to respect and care for other people and, in particular, strangers, visitors and generally vulnerable people.

*Systems Principles*, is a subject that has not been fully subjected to formal inquiry. It is hoped that the study has and shall make a contribution to the subject of family care-giving in HIV & AIDS circumstances. Inferring the value of a systems approach, Glaser asserts that this method like the grounded theory approach allows a researcher the liberty to discover what goes on in a research process, rather than assume what should be going on. For the purpose of this study, the qualitative holistic approach of the grounded theory was utilised in order to understand and explain the experiences of the mothers of the study. Therefore, the details of information that emerged from the collected data inform the conceptual framework, analysis and discussion of this dissertation. Taking into cognisance the feminist methods of enquiry (Stanley and Wise 1983; Bowles and Klein 1983), all attempts were made to allow and encourage the participants to lead the discussions – so as to arrive at utmost understanding of the research problem.

Further, in line with IKS principles and taking the lead from Charmaz (1988), Strauss & Corbin (1990) and Magwaza (2006), the mothers were led to fully participate in the analysis of their own stories. According to these scholars, it is crucial that whilst data is collected, it is concurrently analysed with research participants. This practice ensures that the data analysis process

does not start at the end of a data collection process, thereby limiting opportunities of getting research participants fully involved in the analysis process. Whilst interviewing the mothers, the significance and interpretation of what they were relating was sought. At the end of each interview session I went through the main points of the interview, with the further purpose of identifying the issues that emerged from it. Guided by the grounded theory I identified and coded the issues into issues that have been discussed above. Although some of the issues raised by the study are different from what the Zulu society has for a long time understood, this exploratory study does not claim to represent all mothers facing HIV & AIDS. Nonetheless, it makes compelling statements that should not be ignored in contemporary family and care-giving studies within the context of HIV & AIDS.

Consequently, this research provides an explanation and structural attributes through a sample of few selected families on how society, donors, NGOs, CBOs etc. can understand, acknowledge, accept and subsequently offer informed support for families with similar conditions. Through the *Systems Thinking* approach the study contests a monolithic bias and approach (Hughes, 2002 and Littlejohn, 1999) to social problems. It is in essence an indicator of an appreciation of the fact that a family or families confronted by a similar disease may demonstrate (despite subscribing to the same values

and with same cultural backgrounds) varied and idiosyncratic descriptions of what constitutes a family. Thus, there is a need for communities, scholars and donors to acknowledge and accept that the 'family' comes in various formats and that, just like the associated challenges, it is a construct (Tiblier, *et al.* 1989; Rolland, 1994 and Meyiwa, forthcoming) that ought to be understood in the context of social structures.

Fig. 5.2 CATWOE Analysis of Bhambayi families' problem and solution processes

<b>Customers</b>	<ul style="list-style-type: none"> <li>• Infected and affected family members with health care needs and who are entitled to health &amp; social grants</li> <li>• Caregivers</li> </ul>
<b>Actors</b>	<p><i>Key actors:</i> Dept of Health &amp; Social Development; development practitioners; donors; NGOs; CBOs; Faith-based organisations; support groups</p> <p><i>Responsibility:</i> Projects towards change, better life (transformation); participating in such projects</p>
<b>Transformation</b>	<p><i>Input:</i> Accessible, quality health care services; sensitive officials; consultative planning; advocacy programmes to raise human rights &amp; gender sensitivity awareness</p> <p><i>Output:</i> Healthier family members; successful projects; attainment of holistic well-being; reduction of stigma related incidents &amp; prejudices; better attitudes towards women and HIV &amp; AIDS affected</p>
<b>Worldview</b>	<p><i>Processes:</i> raising living standards of affected families; availing basic accessible amenities; providing resources equitably; enabling &amp; gender sensitive policies</p> <p><i>Outcome:</i> Improved health; better policy implementation</p>
<b>Owners</b>	National and provincial dept of health & social development; local municipality units
<b>Environment</b>	Ill equipped health services; uncommitted health officials; gender biased culture; minimal-nil basic amenities and utilities to ensure sanitation, better health & negative impact on holistic well being

Tabular analysis based on Flood's (1999) theory



## **5.5. Chapter summary**

This chapter has sought to foreground the voices and experiences of the main participants of the Bhambayi study, analyse their stories using 'systems tools' and focus the discussion on how stereotypes and gender misconceptions impact negatively on the HIV & AIDS affected families. Akintola (2004) rightly points out that care-giving is not only gendered but that social processes lead to gendered caring roles among affected families.

Hence, the unequal burden of caring for children cannot be understood without reference to the socialisation process which lies at the roots of the gendering of activities. The above discussion and analyses show that although gender stereotypes apply to both men and women, by employing *System Principle's* it is possible to get to a better understanding of issues facing families and individuals directly affected by HIV & AIDS.

# CHAPTER SIX

## Conclusions

### 6.1 Introduction

This study demonstrates that it ought to be increasingly recognised that HIV & AIDS thrives on, and intensifies inequalities. The inadequate realisation of human rights, in the form of poor service delivery and socio-economic imbalances facilitate the spread of HIV and worsens the impact of HIV & AIDS. Gender inequality and the associated stereotypical beliefs held by communities are critical factors in the HIV & AIDS epidemic. This study asserts that it is essential to gain intense understandings of these challenges before any kind of intervention can be applied. In turn, it submits as well as demonstrates that *Systems Principles* is an apt approach for this purpose.

## **6.2 Recapitulation of main discussion points**

The study and discussion of the dissertation highlights pertinent factors that cannot be ignored about the development and dynamics related to HIV & AIDS. Equally significant is to point out gender biases related to the scourge; for instance, in 1997, four out of ten people living with HIV & AIDS worldwide were women. However, by 2004 women made up almost 50% of people living with HIV & AIDS and in countries like South Africa and communities like Bhambayi (See Chapter 5) where heterosexual transmission is the main mode of HIV transmission the challenges are greater. Women are more likely than men to be infected with HIV. According to UNAIDS report of 2005, the highest 'gender gap' in HIV infection rates was recorded between young women and men between 15-24 years old, hence the need to understand why women and girls are more likely to become infected with HIV. This study has argued that questions of this nature can best be understood through using *Systems Principles* as a tool of analysis.

This study demonstrates that because a growing number of women and girls are being infected with HIV, women and girls make up a significant proportion of those requiring treatment and make up a bigger number of people cared for at home. Further, the experiences of the participants of the

study show that there are many barriers to the realisation of the right to health and to holistic well-being. One of these obstacles relates to inadequate reproductive & sexual health services; difficulty in accessing health services; and negative attitudes of health workers towards HIV & AIDS patients, which results in poor treatment. The neglect of health needs is amongst the barriers to be contended with.

The study indicates that women and girls, more than boys and men, assume responsibility for those who are sick and need care in the home. It also indicates that because young adult women are disproportionately affected by HIV & AIDS, it is often elderly women and young girls who have to assume these roles. The burden of care gets heavier when public and private support services are lacking or unable to cope with the demand. Generally HIV & AIDS impacts women, men, girls and boys differently. This is exemplified in instances where girls, more than boys are compelled to abandon or are taken out of school to help out in the households. In addition, it was found that HIV & AIDS-related stigma and discrimination intertwine with, as well as reinforce existing gender prejudices and inequalities.

### **6.3 Reflecting on the purpose of the study**

The Bhambayi study tried to make correlative relationships between gender, societal beliefs, human rights and HIV & AIDS obvious to those tasked with the development sector – as well as for research purposes. In addition, employing *Systems Principles*, it sought to demonstrate how understandings on these matters can be achieved as well as to give some guidance to development practitioners and researchers on how to keep these complex linkages in mind when they deal with communities in similar circumstances to that of Bhambayi. This dissertation can be used as part of a guide to provide support, by providing multidisciplinary but coherent conceptual frameworks towards a better understanding of social issues that impact such communities. *Systems Principles* can serve as a tool to understand and assess the extent to which development work can contribute towards gender and social equality. This dissertation is meant to help development practitioners and researchers deepen their understanding of the linkages between gender, societal beliefs, human rights and HIV & AIDS and thus respond strategically to these challenges. It is acknowledged that tools and strategies cannot ever be universally applicable. In practice, the suggestions, approaches and strategies presented in this dissertation must be adapted to local circumstances in order to maximise success.

## 6.4 Implications of the research

One cannot overemphasize that, both from the point of view of effectiveness and from the perspective of social justice, HIV & AIDS programming must take account of the vast social, economic inequalities as well as gender dimensions of the HIV & AIDS epidemic. Hence, the study advocates for the use of the tools of *Systems Principles* in addressing the identified complexities. Alongside, as argued by a number of scholars (Leclerc-Madlala, 1999; Pattman & Chege, 2003, etc.), gender equality is possibly the most effective strategy in reducing vulnerability to HIV infection and in enhancing the capabilities of individuals, households and communities to cope with the consequences of HIV & AIDS. Differently but concurring, these scholars assert that the epidemic will cease to spread so rapidly and will no longer cause much devastation when the human rights of women and girls are truly respected and when women and girls are able to engage their male counterparts as equal partners in the household, the community, the workplace, at school, in politics and in many other fora. It is to this end that they suggest some intervention strategies some of which are discussed hereunder.

## 6.5 Intervention opportunities

This study concurs with *Systems Thinking*, HIV & AIDS and feminist scholars that the premise of any strategy towards a change or improved life is that, in order to enhance the effectiveness of HIV & AIDS interventions:

- i) People who are directly affected should be the main stakeholders in attempts to find solutions, hence the need to constantly and actively consult them;
- ii) Any strategic responses must be informed by the experiences and perspectives of the stakeholders whose input should be sought from planning stages;
- iii) Inequalities based on gender relations have to be acknowledged and addressed;
- iv) The reduction of identified inequalities should be integral to the strategic response to HIV & AIDS as much as it should be fundamental in developmental interventions; and
- v) The role of men and boys in promoting gender equality must also be actively sought, accommodated and addressed.

## **6.6 Suggestions for future research and further interventions<sup>32</sup>**

This section is presented in a tabular format and should be read in relation to 6.5 above. The following points are put forward as crucial elements to be considered in future research and to strengthen interventions for developmental purposes towards an improved holistic well-being of those directly affected by HIV & AIDS:

- Informed broad knowledge of options and services for HIV treatment, care and support;
- Information on sexual and reproductive health and rights in dealing with violence against women;
- Imparting the above knowledge at various levels and constantly updating it;
- Providing appropriate and accurate health related information in local languages;
- Providing and updating knowledge as well as appreciating differential gender & socio-economic needs and challenges related to HIV positive people's health and rights;
- Access to good quality, appropriate and comprehensive services for HIV-related care, treatment and support including referrals and follow-up services;

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<sup>32</sup> Some discussion advice provided by "Positive Women Monitoring Change, ICW" (2008).



- Access to knowledge about sexual and reproductive health;
- For all genders - knowledge, possessing and practising good decision making powers - without fear of violence or abuse, in relation to sexual, reproductive, lifestyle, and health choices;
- Treating people (recipients and health services and social development practitioners) with respect and dignity;
- Without prejudice and fear, have an ability to act upon and adhere to medical and psycho-social advice and treatment;
- Knowledge of relevant policies and constantly inviting beneficiaries and practitioners for inputs;
- Involvement at all levels of policy, consultation, design, development and implementation processes;
- Updated knowledge, training and information regarding HIV positive people's health and rights related to care, treatment and support;
- Provision of well-resourced services tailored to meet the needs of HIV positive people and specifically women's different needs;
- Understanding and in a timely way deal with barriers and challenges that HIV positive women have in accessing, adhering to and acting on the information provided by health care and support services;
- User-friendly monitoring and evaluation systems;

- User-friendly, availability and easy access to systems for lodging complaints in order to improve quality, effectiveness and improvement of health and social development services;
- User friendly and adequately interpreted policies and programmes that specifically address HIV positive people's experiences of violence, noting the impact thereof on their holistic well-being;
- Publicised and accessible channels of ensuring responsibility and accountability for policy implementation, evaluation and monitoring;
- Availability of adequate and gender-sensitive budgets to address identified health needs and HIV prevention programmes;
- Resource and support advocacy and awareness campaigns about HIV positive people's health rights and the right to live lives free from violence and abuse; and
- Resource and support for gender sensitive research that advocate for the rights and health promotion of the HIV & AIDS infected and affected.

## **6.7 Limitations**

The descriptions, understandings and analyses provided in this dissertation would be most valuable and effective if those directly affected are not only

involved in monitoring and evaluating the process but also have follow-up procedures put in place.

The study has highlighted the need for a multidisciplinary approach towards minimising the risk and effects of HIV & AIDS on families and individuals. It has further highlighted difficulties in addressing the identified problems. Despite good policies, interventions and programmes, it is apparent that most policies and suggested intervention strategies may be good on paper but hard to implement. This is a limitation that the study acknowledges. However the motivate for a change or for better implementation of strategies, tools and policies cannot be overstated.

As this dissertation has limitations as a part of an MA research degree, some of the experiences and data that emerged as new for me are offered as suggestions for direction of future research.

## **6.8 Concluding remarks**

The Bhambayi case study demonstrates that one consequence of gender inequality is that women are vulnerable in sexual relations and hence more prone to HIV infections than their male counterparts. Related to this is the fact that poverty has a feminine face (Casale & Posel, 2002 and Magwaza, 2008). Advancing this argument, Budlender (2002) contends that poverty; natural disasters, violence, social disruption and the disempowered status of most rural and peri-urban women in southern Africa make it easy for the transmission of HIV infections to thrive. Besides this factor, due to poverty levels, care-giving duties and medical costs are burdensome for the directly involved individuals as well as for the household. There is also a clear link between addressing the impact of the HIV & AIDS epidemic and adequate nutrition with people needing to sell off any assets they have or their skills at ridiculously low rates - in return for food and/ or medication.

For an holistic well-being, sufficient and reasonably priced food is essential for HIV infected individuals and groups, including those in need of anti-retroviral medication. Sadly, in the current economic difficulties it is a struggle to fully realise all the needs of the infected and affected. Adding to

the struggle are skewed gender dynamics, with women mainly bearing the burden of care in the context of AIDS (Luthuli, 2008 and Oxfam, 2008).

Also, poverty and food insecurity tend to impact negatively on women more than on other groups in families and poor communities.

This study found that there is a significant link between poverty, violence and HIV & AIDS which in turn makes the task of care-giving harder. Aligned with this link was the finding that violence is a reality in the lives of women and girls in many households and communities of Bhambayi. Leclerc-Madlala (1999) and Zimba & Mclerney (2001) maintains that such a situation has dire consequences in terms of worsening poverty levels as children lose parents, add-on to an already high rate of children orphaned by AIDS. They in turn are in dire need of care and financial support. This unfavourable status quo gets worsened by the fact that South Africa is a country with a complex and not-easily-accessible social grant system. In other cases, extended kin take in orphans but this ideal is dwindling (de la Porte, 2008). Such circumstances have led Watkinson and Makgetla (2002) to suggest special nutrition schemes for people with HIV and their families and more effective welfare grants.

## References

Ackoff, R.L. (1971). "Towards a System of Systems Approach". In *Management Science*, 17 (11). 661-671.

Ackoff, R.L. (1974). *Redesigning the Future: A Systems Approach to Societal Problems*. New York: N.Y. Wiley.

Adams, R. and He, J. J. (1995). "*Sources of Income, Inequality and Poverty in Rural Pakistan*". Edcon Papers. Washington D.C: International Food Policy Research Institute.

African Journal of Indigenous Knowledge Systems, Vol. 2. Publication of 2003.

Agar, M.H. (1980). *The Professional Stranger: An Informal Introduction to Ethnography*. New York: Academic Press.

Aggleton, P. et al. (1991). *AIDS Responses: Intervention and Care*. London: The Falmer Press.

AIDS Epidemic Update Report, December 2003.

Akintola, O.O. (2004). "Home-based Care: A Gendered Analysis of Informal Caregiving for People Living with HIV/AIDS in a Semi-rural South African Setting" . Unpublished PhD Dissertation. Durban: University of KwaZulu-Natal.

Albrow, M. (1999). *Sociology: The Basics*. London & New York: Routledge.

Baro, M., & Deubel, F. (2006). Persistent Hunger: Perspectives on Vulnerability, Famine, and Food Security in Sub-Saharan Africa. *Annual review of Anthropology*. 35:521-38

Beer, S. (1985). *Diagnosing the System for Organisations*. Chichester: Wiley.

Beijing Platform of Action Report (1995).

Benjamin, M. (2005). "An Assessment of the Bhambayi Community with the View of Planning an Improved Home-Based Care Programme for People Living with Aids". Unpublished MTech Dissertation. Durban Institute of Technology.

Bertrand, I. and Hughes, P. (2005). *Media Research Methods: Audiences, Institutions, Texts*. New York: Palgrave MacMillan.

Bertram J. Cohler, (1981). *Mothers, Grandmothers, and Daughters: Personality and Childcare in Three-Generation Families*. John Wiley & Sons Inc Publishers

Bettie, J. (2003). *Women without Class: Girls, Race and Identity*. Los Angeles: University of California Press.

Bilton, T. et al. (1996). *Introductory Sociology*. 3<sup>rd</sup> Edition. London: MacMillan Press.

Boland, R. (1985) "Phenomenology: A Preferred Approach to Research in Information Systems," in E. Mumford et al. (eds.), *Research Methods in Information Systems*, Amsterdam: NorthHolland.

Bowles, G. and Klein, R.D. (eds.), (1983) *Theories of Women's Studies*, London: Routledge & Kegan Paul.

Bowers, B.F. and Myers, B.J. (1999). "Grandmothers Providing Care for Grandchildren: Consequences of Various Levels of Caregiving", *Family Relations*: 48 (3). 303-311.

Brettel, C. and Sargent, C. (eds.) (2001). 3<sup>rd</sup> Edition. *Gender in Cross-Cultural Perspective*. New Jersey: Prentice Hall.

Brody M. (1992). *Mary Wollstonecraft: Sexuality and Women's Right*, In Spender, D (ed.) *Feminist Theories*. London: The Women's Press. Pp 41-59.

Brookes, H., Shisana O. and Richter, L. (2004). *The National Household HIV Prevalence and Risk Survey of South African Children*. Pretoria: HSRC Publication.

Bryant, C., and Kappaz, C. 2005. *Reducing poverty, building peace*. Bloomfield, CT: Kumarian Press.

Bubolz, M. and Sontag, S. (1993). "Human Ecological Theory". In P. G. Boss, et al. (Eds.). *Sourcebook of Family Theories and Methods: A Contextual Approach*. New York: Plenum Press.

Budlender, D. 2002. Why should we care about unpaid care work? A guidebook prepared for the UNIFEM Southern Africa Regional Office. Harare: Unifem.

Bukuluki, P., Mugumya, F., Neema, S., Kafuko, A., and Ochen, E. (2007-2008), Gender, Food Security and AIDS in Internally Displaced People's Camps in Uganda: Implications for HIV Responsive Policy and Programming. [www.ifpri.org/renewal/pdf/RFbrief17.pdf](http://www.ifpri.org/renewal/pdf/RFbrief17.pdf). Accessed on 26 September 2009.



Burnard, O. (1992). *Perceptions of AIDS Counseling*. Great Britain: Athenaeum Press Ltd.

Burr, V. (1998). "Overview, Realism, Relativism, Social Constructionism and Discourse". In I. Parker (ed.) *Social Constructionism, Discourse and Realism*. Great Britain: Cambridge University Press.

Butler, J. (1999). *Gender Trouble: Feminism and the Subversion of Identity*. New York & London: Routledge.

Campbell, C. and Foulis, C. (2002). "Creating Contexts that Support Youth-led HIV Prevention in Schools". *Society in Transition*. 33 (3). 312-329.

Campbell, C. (2005). *Understanding and Challenging HIV/AIDS Stigma*. Pietermaritzburg: University of KwaZulu-Natal Press.

Casale D and Posel D (2002) "The Continued Feminisation of the Labour Force in South Africa: An Analysis of Recent Data and Trends", *South African Journal of Economics*, 70(1), 156-184.

Cavallo, R.E. (1982). *Systems Methodology in Social Science Research: Recent Developments*. Kluwer Nijhoff: Boston.

Charmaz, K. (1988). "The Grounded Theory Method: An Explication and Interpretation." *Contemporary Field Research*. Ed. Robert. M. Emerson. Boston: Little-Brown.

Checkland, P. (1981). *Systems Thinking, Systems Practice*. Chichester: Wiley.

Checkland, P. (1985). "From Optimising to Learning: A Development of Systems Thinking for the 1990s". In R.L. Flood and M.C. Jackson (eds.). *Critical Systems Thinking: Directed Readings*. Chichester: Wiley.

Checkland, P. and Scholes, J. (1999). *Soft Systems Methodology in Action: Includes a 30-Year Retrospective*. New York: Wiley.

Churchman, C.W. (1968). *The Systems Approach*. New York: Delta.

Coetzee, J. K., Graf, J., Hendricks, F., Wood, G. (2001). *Development: Theory, Policy and Practice*. Oxford University Press: Cape Town.

Connell, R. (2005). "Change Among the Gatekeepers: Men, Masculinities and Gender Equality in the Global Arena". In *Signs: Journal of Women in Culture and Society*, Vol. 30, (3). 1801-1825.

Corbett J. (1989). "Vulnerability, How to Cope". AIDS Bulletin, volume 20 numbers 2 April 1989.

Christie-Dever, B. (1996). AIDS. *What Teens Needs to Know*. California: The Learning Works inc.

Dahlbom, B. and Mathiassen, L. (1993). *Computers in Context: The Philosophy and Practice of Systems Design*. Oxford: NCC Blackwell.

de la Porte, S. and Meyiwa, T. (forthcoming). "Grandmothers and Grand-mothering" (In press).

de la Rey, C. (1992). "Culture, Tradition and Gender: Let's talk about it". In *Agenda*, 13. 78-86.

Denis, P. and Makiwane, N. (2003). "Stories of Love, Pain and Courage. Aids Orphans and Memory Boxes" *Oral History* 3 (1/2): 66-74.

Doucet, A. (2006). *Do Men Mother?* Toronto: University of Toronto Press.

Dudwick, N. et al. (2003). *When Things Fall Apart*. Washington D.C: *The World Bank*.

Evans, M. (2003). "The Gendered Self". In K. Milton (ed.) *Gender and Social Theory*. Bucks: Open University.

Farmer, P. et al. (eds.) (1996). *Women, Poverty, and AIDS: Sex, Drugs, and Structural Violence*. Monroe: Common Courage Press.

Flood, R.L. (1999). *Rethinking the Fifth Discipline*. Routledge: USA and Canada.

Frydenberg, E. (1991). *Learning to Cope*. New York: Oxford University Press.

Glaser, B.G. and Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Sociology Press.

Goede, R. (2005). "A Framework for the Explicit Use of Specific Systems Thinking Methodologies in Data-Driven Decision Support System Development". Unpublished PhD Dissertation. Pretoria: University of Pretoria.

Gouldner, A. (1971). *The Coming Crisis in Western Sociology*. New York: Basic Books.

Gupta, G.R. and Weiss, E. (1996). *Women and AIDS: Developing a New Health Strategy*. Washington: International Centre for Research on Women.

Habermas, J. (1974). *Theory and practice*. London: Heinemann.

Hagenaars, A. (1986). *The Perception of Poverty*. Amsterdam: North Holland.

Harris, I. (1995). *Messages Men Hear: Constructing Masculinities*. London: Taylor & Francis Ltd.

Harvey, L. (1990). *Critical Social Research*. London: Unwin Hyman.

Hlanze, Z., Gama, T. & Mondlane, S., 2005. The impact of HIV/AIDS and Drought on local Knowledge systems for Agro biodiversity and Food Security, Links Project, Fao-Links Swaziland.

Hughes, C. (2002). *Key Concepts in Feminist Theory and Research*. London, Thousand Oaks & New Delhi: Sage Publications.

Human Sciences Research Council Report. 2004. Food security in South Africa: Key policy issues for the Medium Term. Pretoria: HSRC.

Infante, D.A. et al. (1997). *Building Communication Theory*. Prospect Heights, Illinois: Waveland Press.

IPAS (2005). A Multi-country Study on HIV Positive Women's Experiences in Accessing Health Services. New York: IPAS.

Jackson, H. (2002). *Aids Africa: Continent in Crisis*. Zimbabwe: SAfAIDS.

Jackson, M.C. (1991). *Systems Methodology for the Management Sciences*. New York: Plenum.

Jackson, M.C. (2001). "Critical Systems Thinking and Practice". *European Journal of Operational Research*, 128. 233-244.

Johnson, R.W (1994). "The Last Days of Bhambayi". In *London Review of Books*. Volume 16 (1). 9-10.

Jones, S. (1992). 'Children on the Move: Parenting, Mobility and Birth-status among Migrants', *Questionable Issue: Illegitimacy in South Africa*. London: Oxford University Press.

Kabeer N. Poverty, policy and AIDS. IDS Bulletin Volume 27 Number 1 January 1996.

Kay, J.J. and Foster, J.A. (1999). "About teaching Systems Thinking." In G, Savage and P. Roe (eds.) *Proceedings of the HKK Conference*, 14-16 June, 1999. Ontario: University of Waterloo: 78-104.

Kaplan, B. and Maxwell, J.A. (1994) "Qualitative Research Methods for Evaluating Computer Information Systems," in J.G Anderson et al. (eds) *Evaluating Health Care Information Systems: Methods and Applications*, Thousand Oaks, CA: Sage.

Kelly, K. & Marrengane, N. (2004). South African Cities and HIV/AIDS: Challenges and responses. South African Cities Network, Johannesburg, South Africa. Kimmel, M. (ed.) (2001). *Changing Men*. California: Sage.

KwaZulu-Natal Provincial Department of Education *HIV/AIDS Strategy* (2007-2011). Pietermaritzburg, KwaZulu-Natal, South Africa.

Laarmans, R. (1999). *Communicatie Zonder Mensen*. Amsterdam: Uitgeverij Boom.

Leclerc-Madlala, S. (1999). "Demonizing Women in the era of Aids: An Analysis of Gendered Construction of HIV/AIDS in KZN". Unpublished PhD Dissertation. Durban: University of Natal.

Lillejord, S. and Soreide, G. (2003). "Tell me your Story: Using Narratives from Interviews to Understand Indigenous Knowledge", *Indilinga* Vol.2 (1), 89-97.

Littlejohn, S.W. (1999)

Littlejohn, S.W. (2001). *Theories of Human Communication*. Belmont, CA: Wadsworth/ Thomson Learning.

Lorber, J. (2001). "Night to His Day: The Social Construction of Gender". In Cohen, T.F. (Ed.). *Men and Masculinity: A Text Reader*. California: Wadsworth.

Luthuli, E.N. (2008). "The Lives and Experiences of HIV Positive Teenage Learners: A Case Study of Intshanga Schools of KwaZulu-Natal". Unpublished MA Dissertation. Durban: University of KwaZulu-Natal.

Macklin, E. (Ed.) (1989). *AIDS and Families*. Binghamton, NY: Harrington Park Press.

Magwaza (Meyiwa),<sup>33</sup> T. (2008). "Effects of Domestic Workers' Act in South Africa: A Steep Road to Recognition". In *Agenda* 78: 79-92.

Magwaza (Meyiwa), T. (2009). "Questioning the Need to Balance Family and Work Duties: Experiences of a Black South African Woman". 3-16 in Naidoo, K. and Patel, F. (eds.) *Working Women: Stories of Strive, Struggle and Survival*. New Delhi: Sage.

Makhaye, G. (2005). "Young Men". In S. S. Abdool Karim & Q. Abdool Karim (Eds.) *HIV/Aids in South Africa*. Cambridge: Cambridge University Press.

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<sup>33</sup> I have used both these names in my scholarly work, Magwaza (earlier work) and Meyiwa (recent work, from 2009 onwards).

Manchester, J. (2004). "Hope, Involvement and Vision: Reflections on Positive Women's Activism around HIV." In *Transformation* 54: 85-103.

McAllister, A. (2002). "The Benefits of being a Nurse in Critical Social Research Practice". In *Qualitative Health Research*, Vol. 12 (5). 700-712.

McRobbie, A. (2000). *Feminism and Youth Culture*. London: MacMillan Press.

Meyiwa, T. (forthcoming book chapter) "Contemporary Mothering Practices in the Context of HIV and AIDS: A South African Case Study".

Metro Beat Magazine, March Issue, (2005).

Midgeley, G. (2000). *Systemic Intervention: Philosophy, Methodology and Practice (Contemporary Systems Thinking)*. New York: Kluwer Academic/Plenum.

Midgley, G. (Ed.) (2003). *Systems Thinking*. London: Sage.

Mills, J.S. (1996). *The Subjection of Women*. In Miriam Schneir (ed.). *The Vintage Book of Historical Feminism*. London: Vintage Press. Pp 162-178.

Mingers, J. (1995). "Using Soft Systems Methodology in the Design of Information Systems". In F. Stowell (ed.). *Information Systems Provision: The Contribution of Soft Systems Methodology*. London: McGraw-Hill.

Morrell, R. (2001). "The Times of Change: Men and Masculinity in South Africa" In R. Morrell (ed.) *Changing Men in Southern Africa*. South Africa: University of Natal.

Morrell R. and Ouzgane L. 2005. (Eds.) *African Masculinities*. New York: Palgrave MacMillan.

Morrell R. and Ritcher L. 2006. *Baba: Men and Fatherhood in South Africa*. Cape Town: HSRC Press.

Mulugeta, E. 2008. Crossing the Hurdle: Survival Strategies of Poor Women. *EASSRR*, 24(1): 41-80.

Muthuki, F. (2005). "Trends or Counter Trends? The Gender Identity Dilemma Facing Zulu Married Men and Women at the University of KwaZulu-Natal". Unpublished MA Dissertation. Durban: University of KwaZulu-Natal.

Msimang, C.T. (1975). *Kusadliwa Ngoludala*. Pietermaritzburg: Shuter and Shooter.

Ndlovu, N. & Daswa, R. (2006). Review of progress and expenditure on the Comprehensive Plan for HIV and AIDS for South Africa. IDASA AIDS Budget Unit. <http://www.idasa.org.za>. Accessed on 13 November 2009.

Ngcongco, R. (1993). "Power, Culture and the African Woman". In *Agenda*, 19. 5-10.

*NMF/HRSC Survey*, 2005.

Ntiisa, J.K. (2007). "An Investigation into the Effectiveness of Systems Thinking Approach in Illuminating Understanding of Poverty as a Complex Situation: A South African Case Study." Unpublished MA Dissertation. Durban: University of KwaZulu-Natal.

Ombe, Z. (2003). "Indigenous Land Use Management in Lower Changane and Chibuto: Sacred and Profane Desacralisation and Recovery, Private Transgression", *Indilinga* Vol.2 (1), 1-9.

Osmani, S. (1992). *Nutrition and Poverty*. United States: Oxford University Press.



Pattman, R. and Chege, F. (2003) *Finding Our Voices, Gendered and Sexual Identities and HIV / AIDS in Education*. Unicef Eastern and Southern Africa.

Plant, M. (1990). *AIDS, Drugs and Prostitution*. London: Routledge.

Richardson, D. (1994). 'AIDS: Issues for Feminism'. In L. Doyal, J. Naidoo, and T. Wilton (eds.) *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis.

Rolland, J. (1994). *Families, Illness & Disability*. NY: Basic Books.

Ruddick, S. (1994). *Maternal Thinking*. Boston: Beacon Press.

Seabrooke, J. (2003). *The No Nonsense Guide to World Poverty*. London: Verso Books.

Senge, P. (1994). *The Fifth Discipline Field Book: Strategies and Tools for Building a Learning Organisation*. Nicholas Brealey: London.

Shikumo, E. A. (2008). "Negotiating Masculinities: Perspectives of Male Students at the University of KwaZulu-Natal". Unpublished MA Dissertation. Durban: University of KwaZulu-Natal.

Sienaert, E. et al. (eds.) (1991). *Oral Tradition and Innovation: New Wine in Old Bottles?* Selected conference papers. University of Natal: Oral Documentation Centre.

Sokoyo, G. O. (2003). "Socio-cultural Constructions of Gender Roles and Psychological Wellbeing in Farm-Families of Ogun State, Nigeria: Exploring the Complexities". Unpublished PhD Dissertation. Durban: University of Natal.

Songwathana, P. (2001). "Women and Aids Caregiving: Women's Work?" In *Health Care for Women International*, 22(3). 263-279.

South African Cities and HIV/AIDS Report. Challenges and Responses, 2004. London: Routledge.

South African Report on *National Department of Health Antenatal Surveys*, 2002-2006

Spender, D. (1982). *Women of Ideas & What Men Have Done to Them*. London & Boston: Ark Paperbacks.

Stanley, L. Wise s. (1983). "'Back into the Personal' or Our Attempt to Construct 'Feminist Research.'" *Theories of Women's Studies*. Eds. Gloria Bowles and Renate, D. Klein. London: Routledge.

Stajduhar, K. I. (1998). "Palliative Care at Home: Reflections on HIV/AIDS Family Care giving Experiences." In *Journal of Palliative Care*, 14 (2). 14-22.

Steans, J. (1998). 'Gender, Feminism and International Relations'. In J. Steans, *Gender and International Relations: An Introduction*. New Jersey: Rutgers University.

Stockard J. and Johnson M. (1980). *Sex Roles: Sex Inequality & Sex Role Development*. New Jersey: Prentice Hall.

Strauss, A. and Corbin, J. M. (1990) *Basics of Qualitative Research*. Newbury Park, California: Sage.

Strauss, A. and Corbin, J. M. (1990) *Basics of Qualitative Research*. Newbury Park, California: Sage.

Strijbos, S. (2000). "Systems Methodologies for Managing our Technological Society: Towards a "Disclosive Thinking". In *Journal of Applied Systems Studies*, 1(2). 159-181.

Tallis, V. (1997a). "AIDS is a Crisis for Women". In *Agenda*, 39. 6-14.

Tallis, V (1997b) 'An Exploratory Investigation into the Psychosocial Impact of an HIV Positive Diagnosis in a Small Sample of Pregnant Women, with Special Reference to KwaZulu-Natal'. Unpublished Thesis. Department of Social Work, University of Natal, Durban.

Tallis, V. (Guest Ed.) (1998). *Agenda*, 39 – Focus Issue on AIDS and Women.

Taylor, S. and Field, D. (2003). *Sociology of Health and Health Care*. Australia: Blackwell Publishing.

Thompson, E. A. (2000). "Mothers' Experiences of an Adult Child's HIV/AIDS Diagnosis: Maternal Responses to and Resolutions of Accountability for AIDS." In *Family Relations* 49 (2). 15-164.

Tiblier, K. B. et al. (1989). "Therapeutic Issues when Dealing with Families of Persons with AIDS." *Aids and Families*. Ed. Eleanor, Macklin. New York: Harrington Park.

Turshen, M. (1991). *Women and Health in Africa*. Africa Word Press.

UNAIDS, 2003, 2004, 2005, 2006, 2007. Reports on the Global AIDS Epidemic.

Uys, L.R. (2001). "Evaluation of Integrated Community-based Home Care Model. *Curations*, 75-82.

Uys, L.R. (2002). "The Practice of Community Caregivers in a Home-based HIV/AIDS Project in South Africa. In *Journal of Clinical Nursing*. 11. 99-108.

Vaines, E. (1988). "The Reflective Professional: Reflecting on Helping for the 21<sup>st</sup> century". *Series: People and Practice: International Perspective in Home Economics*.

Vaines, E. (1997). A Family Perspective on Everyday Life: A Narrative Approach. *Proceedings of the Canadian Home Economics Association: Community Canada, Reaching in. Reaching Out*. July 9-12, Victoria, Canada.

van de Wouwer P. (2005) "Gender stereotypes in HIV / AIDS discourse. In *Language Matters*. 36 (2):148-161.

Von Bertalanffy, L. (1968). *General Systems Theory: Foundations, Development, Applications*. Revised edition. New York: George Braziller.

Walmsley, E. (2008). "Raised by Another Mother: Informal Fostering and Kinship Ambiguities in Northwest Ecuador", In *The Journal of Latin American and Caribbean Anthropology*. 13:1. 168-195.

White, H. and Killick, T. (2001). *African Poverty at the Millennium*. Washington D.C: The World Bank.

Whiteside, A. and Sunter, C. (2000). *Aids: The Challenge for South Africa*. Cape Town: Human & Rousseau (Pty) Ltd.

Whitten, J.L. et al. (2004). *Systems Analysis and Design Methods* (6<sup>th</sup> ed.). Boston: McGraw-Hill.

Wollstonecraft, M. (1996), *A Vindication of the Rights of Women*. In Schneir, M (ed.). *The Vintage book of Historical Feminism*. London: Vintage Press. Pp 05-16.

Wong-Wylie, G. (1997). "Family Incidents: Impacting Hope of Persons with HIV/AIDS". Unpublished MA Dissertation. Edmonton, Alberta: Canada.

Youle, M. et al. (1988). *AIDS Therapeutics in HIV Disease*. New York: Churchill Livingstone.

Zimba, E.M. and Mclerney, P.A. (2001). "The Knowledge and Practices of Primary Caregivers Regarding Home-based Care of HIV/AIDS Children in Blantyre, Malawi. *Curations*, 83-91.

## Internet Sources

Bukuluki, P., Mugumya, F., Neema, S., Kafuko, A., and Ochen, E. (2007-2008), Gender, Food Security and AIDS in Internally Displaced People's Camps in Uganda: Implications for HIV Responsive Policy and Programming. [www.ifpri.org/renewal/pdf/RFbrief17.pdf](http://www.ifpri.org/renewal/pdf/RFbrief17.pdf). Accessed on 26 September 2009.

EThekweni Municipality Geographical Information Systems

Gender Stereotypes Compromise Sexual Health;  
[www.fhi.org/en/RH/Pubs/Network/v214/NWvol21-4gendroles.htm](http://www.fhi.org/en/RH/Pubs/Network/v214/NWvol21-4gendroles.htm),  
Network: 2002, Vol. 21, No. 4, Accessed on 12 November 2009.

<http://citymaps.durban.gov.za/zippeddata/DataFiles.asp>. Accessed on 12 November 2009.

<http://www.managementhelp.org/systems/systems.htm>. Accessed on 14 January 2008.

<http://www.managementhelp.org>. (Accessed 28 March 2008).

Magwaza, T. (2003). "Perceptions and Experiences of Motherhood: A Study of Black and White Mothers of Durban, South Africa." *Jenda: A Journal of Culture and African Women Studies*. Available from [www.jendajournal.com/jenda/issue4/magwaza.html](http://www.jendajournal.com/jenda/issue4/magwaza.html). (Accessed November 29 2006).

Ndlovu, N. & Daswa, R. (2006) Review of progress and expenditure on the Comprehensive Plan for HIV and AIDS for South Africa. IDASA AIDS Budget Unit. <http://www.idasa.org.za>. Accessed on 13 November 2009.

Oxfam, 2008. Our Focus. Available online at [www.oxfam.org.au/world/africa/south africa/](http://www.oxfam.org.au/world/africa/south%20africa/) Accessed on 8 July 2009.

Positive Women Monitoring Change. ICW (International Community of Women Living with HIV & AIDS). September 2008.  
<http://www.icw.org/node/242>. Accessed on 17 May 2009.

Ren, A. (2006). <http://www.hampshire.edu/cms/index.php?id=8308>.

February 2007. *South African Statistics on HIV/AIDS*.  
<http://www.avert.org/safricastats.htm>. Accessed 18 September 2008.

St Martin's Church. [www.stmartinschurch.co.za](http://www.stmartinschurch.co.za). Accessed 20 October 2009.

Sullivan, GV (2002 September) Reflexivity and Subjectivity in Qualitative Research: The Utility of a Wittgensteinian Framework [29 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [Online Journal], 3(3). <http://www.qualitative-research.net/fqs-texte/3-02/0-02sullivan-e.htm>. Accessed on 17 January 2008.

Towards an Anti-Poverty Strategy for South Africa- discussion document, 2008 [http://ltnw.creamermedia.co.za/articles/attachments/17505 antipoverty 2008.pdf](http://ltnw.creamermedia.co.za/articles/attachments/17505_antipoverty_2008.pdf). Accessed on 18 August 2009.

Watkinson, E. and Makgetla, N. 2002. South Africa's Food Security Crisis. <http://www.naledi.org.za/pubs/2002/watkinson1.pdf>. Accessed on 17 August 2009.

White-Means. S.I. and Chang, C.F (1994). "Informal Caregivers' Leisure Time and Stress" In *Journal of Family and Economic Issues*, 15 92). 117-136.

Wikipedia Encyclopedia. N.d. Social Constructionism.

<http://en.wikipedia.org/wiki/socialconstructionism>. Accessed on 18 August 2007.

WHO (2000). Caring for Family Members with HIV/AIDS and other Chronic Illnesses. The Impact on Older Women and Girls. Geneva: The World Health Organisation.



# Appendices

## Appendix 1: Letter to participants

UNIVERSITY OF KWAZULU-NATAL

SCHOOL OF LEADERSHIP STUDIES

Dear Research Participant,

**Proposed Qualification:** Master of Commerce in Organisation and Management Studies

**Researcher:** Thenjiwe Meyiwa (**Stud. No. 901350570**)

**Supervisor:** Prof. Suzanne Leclerc-Madlala (031) 2425612

**Research Office:** Ms. P. Ximba 031-2603587

I, **THENJIWE MEYIWA** an MA student, at the School of Leadership Studies, of the University of KwaZulu-Natal am conducting research. You are invited to participate in a research project entitled “Understanding HIV/AIDS effects through systems principles: A case study of home-based care giving in a peri-urban community of KwaZulu-Natal”. The aim of this study is to: to explore and explain the manner in which Systems Thinking methodology can be applied in an attempt to understand the impact of HIV/AIDS on families and individuals that take care of people affected by the disease.

Through your participation I hope to:

- Identify issues that may be interconnected and interdependent – that affect families caring for people with HIV/AIDS
- Examine the impact that each issue has in another, i.e. the causal links between issues
- Examine the construction and meaning of the terms ‘family’ and ‘mother’ in an HIV/AIDS context

The results of the survey are intended to contribute to the literature on home-based care-giving.

Your participation in this project is voluntary. You may refuse to participate or withdraw from the project at any time with no negative consequence. There will be no monetary gain from participating in this survey. Confidentiality and anonymity of records identifying you as a participant will be maintained by the School of Leadership Studies, UKZN.

If you have any questions or concerns about participating in this study, you may contact me or my supervisor at the numbers listed above.

The interview should take you about 90 minutes to complete.

Sincerely,

Investigator’s signature \_\_\_\_\_ Date \_\_\_\_\_

**This page is to be retained by the participant**

UNIVERSITY OF KWAZULU-NATAL

SCHOOL OF LEADERSHIP STUDIES

Appendix 2: Consent form

**Proposed Qualification:** Master of Commerce in Organisation and Management Studies

**Researcher:** Thenjiwe Meyiwa (Stud. No. 901350570)

**Supervisor:** Prof. Suzanne Leclerc-Madlala (031) 2425612

**Research Office:** Ms. P. Ximba 031-2603587

**CONSENT**

I..... (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

**EQUIVALENT SIGNAGE/ SIGNATURE OF PARTICIPANT**

.....

**DATE**

.....

## INTERVIEW QUESTIONS<sup>34</sup>

### Appendix 3: Interview questions

**STUDENT NAME:** Thenjiwe Meyiwa (901350570)

**PROJECT TITLE:** Understanding HIV/AIDS effects through systems principles: A case study of home-based care in Bhambayi

#### **A. Interview Details**

1. Name & Surname:.....
2. Occupation: .....
3. Date: .....
4. Place: .....
5. Time: .....
6. Mood of the participant prior to interview (If applicable): .....
7. Mood of the participant after the interview (If applicable): .....

#### **B Biographic Details**

1. Codename: .....
2. Gender: .....
3. Age: .....
4. Marital status: .....
5. Language group: .....
6. Number of children cared for: .....
7. Address/Origin: .....

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<sup>34</sup> Translated into Zulu.

**C. Main Questions: (open-ended, translated)**

1. Who makes up your family?
2. Is your family limited to blood relatives?
3. Are you a caregiver?
4. Are any of the people/ children you care for HIV positive?
5. What/ how are you or your 'family' involved in the specific care giving?
6. Do you receive help of any kind towards care giving?
7. Take me through your normal day as a caregiver.
8. Do you experience any challenges with your care giving duties?
9. If YES, what have been your coping strategies?

*Appendix 4: Main Questions (in the Zulu language)*

1. Ngobani abasemndenini wakho, okungukuthi amalungu awo?
2. Ngakube amalungu omndeni wakho awegazi wodwa noma wonke?
3. Ungunompilo noma uzithatha ngokuthi 'ungumzali' wabantwana?
4. Kulaba obabhekelelayo bakhona yini abanesifo?
5. Yini ngqo oyenzayo ekubhekeleleni abantwana?
6. Likhona usizo noma ukuxhaseka ngandlela thile okutholayo?
7. Ake ungibeke esithombeni ngezinto ozenza usuku nosuku ekubhekeleleni abantwana.

8. Zikhona izingqinamba ohlangabezana nazo?

9. Uma zikhona, yiziphi izindlela ozisebenzisayo ukulwisana nalezo zingqinamba?

**Appendix 5: Abbreviated samples/ excerpts from transcribed data<sup>35</sup>**

1. Ngobani abasemndenini wakho, okungukuthi amalungu awo?

- *Ngingabala ngithini nje ngane yami konje? Cha bona baningi, nokho ukubaluleka kwabo kwahlukile ngenxa yendlela esixhumana ngayo. Isimo sami senza ukuthi abanye abantu bangibuke ngehlo elahlukile. Sebaya ngokuncipha abantu engibathatha njengomndeni nakuba beyizihlobo zegazi.*
- *Uyazi akuyi ngegazi nje kuphela. Bheka ngoba mina zonke izingane engizibhekile kanye nabantu abasondelene nami akubona abegazi. Okungukuthi yizimo dadewethu empeleni ezilawula ubuhlobo.*

2. Ngakube amalungu omndeni wakho awegazi wodwa noma wonke?

- *Buka mina nje ngibheka izingane eningi kangakanani okungezona ezami. Nakuba ezami izingane engazizala zimbili vo kodwa leli khaya ngeleziningi izingane, ezindala nezincane. Ukuhamba komyeni wami kudala kwenza ngasala nesikhulu isikhala. Nganginethemba lomndeni omkhulu, izingane. Kodwa uNkululunkulu emuhle ungibusise ngalezi zingane ezigcwalisa impilo yami. Ngizithatha njengegazi lami.*
- *Abahlobo bami abaningi esixhumana nabo ngenxa yokusizana sengabathatha njengamalunga omndeni wami – sebefana nje, empeleni bayilo igazi lami, lomoya nokho. Ukuxhumana kukhulu.*

3. Ungunompilo noma uzithatha ngokuthi 'ungumzali' wabantwana?

- *Ngingumama walezi zingane engihlala nazo. (Noma uyindoda uzithatha njengomama?). Ngiyindonda yebo, kodwa konke enikwenzayo kufana ncamashi nonina walaba bantwana.*

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<sup>35</sup> This appendix compromise of the questions posed to the participants and some of the related responses given.

- *Nginguninakhulu wabo, hhayi-bo empelelni ngingukhokho. Nokho ngingumzali woqobo, unina wabo, onjengomama wabo. Ngale kokuthi bayigazi lami ngifana nomama, empeleni ngungumama walezi ngane. Onina bedlula emhlabeni. Yiso isifo njalo, akukho okunye. Lesi sifo seza nolukhulu ushintsho.*

4. Kulaba obabhekelelayo bakhona yini abanesifo?

- *Zombili izingane zakwethu zimsulwa kodwa isizathu sokuba yizintandane yiso isifo. Kokhu kwenza ukuthi izihlobo zisibukele phansi, zisuhlukumeze kanjalo futhi zisibize ngezici. Ekuhlaleni kwethu nezihlobo ngemva kokuhamba kumama saba nenkinga. ... sesagcina sizibuyelele khona la endlini kamama.*
- *Yebo sisi kwababili engibabhekayo banaso. Yinkinga phela ngoba badinga ukubhekelelwa ngendlela eyahlukile bona kunezingane ezijwayelekile. Nhlanhla leyo, ngaqeqeshwa kancanyana ngokuhlenga abantu abanegciwane.*

5. Yini ngqo oyenzayo ekubhekeleleni abantwana?

- *Kuningi bo, ngingabala ngithini nje konje? Kusukela ekubagezeni, ngibenzele ukudla. Niqiniseko ukuthi banezidingo njll. Konke kodwa kufuna imali – le kodwa engekho. Kunzima akulula neze, ikakhulu njengoba umsebenzi ungabonwa nje. Kuyangisiza ukudayisa kodwa.*
- *Ngingumxhiliba nginjalo kodwa kudinga ngingene ntshi emsebenzini wokuba ngumama. Nokho angikhonondi. Lokhu ngikuthatha njengesiphiwo esivela kumdali nasemadlozini. Uyacabanga kodwa ukuthi ukuba lezi zingane zazingekho ukuthi ngabe ngiyinhlwa, ngihlalancedwa. Muhle uJehova.*

6. Lukhona usizo noma ukuxhaseka ngandlela thile okutholayo?

- *Kuphi kodwa khona? Njengoba bengenazo kwazitifiketi ngumqansa. Konje ngubani ongangilalela uma nithi ngizofuna izitifiketi zokuzalwa? Ngale kokuthi ngihlale ngizwa mhla kwasa ukuthi kunezinkinga ezingapheli – kwamina njengomuntu omncane ongenalo kwapasi lelo giyoba nenkinga. Angiboni*



*ukuthi ukhona ongangilalela. Ekukhulumeni kwami nabantu abaningi sengizwile kodwa ukuthi kudinag ukuba ngixhumane nama social worker.*

- *Ngingeke ngakhala njengabaniningi. Ngale kwemfalakahlanga ephuma kuhulumeni, kunabaxhasi baphesheya abalekelelayo.*

7. Ake ungibeke esithombeni ngezinto ozenza usuku nosuku ekubhekeleleni abantwana.

- *Ukudla, isikole, umtholampilo noma amaphilisi, ukudayisa ukuze ngithole imadlanga kanye nokuqikelela ukuthi zonke izinto zesikole zimi ngomumo.*
- *Mukhulu lo muzi walapha. Nemisebenzi yakhona kanjalo nayo mikhulu. Kodwa-ke bakhona abasebenzi abangisizayo ukubhekelela lezi ngane. Ngaphandle kwabo angiboni ukuthi ngingaya kanjani phambili.*

8. Zikhona izingqinamba ohlangabezana nazo?

- *ZinganoZulu enya emakheni ngane yami – kodwa ingxenye yempilo. Indawo esihlala kuyo iqhelile emitholampilo kanti akuhambeki. Uma sekunesidingo sokuthi kufike imoto qhathatha lapha egcekeni kusa ngokunye. Uhulumeni kudinga asilungiselele.*
- *Wakhuluma indaba – nakuba kufundiswa mhla kwasa ngesifo lesi kodwa abantu bayakubandlulula. Uzwa ezinkulumeni ubone nasekwenzeni. Kodwa ngokuhamba kwesikhathi uyabona ukuthi kuba ngconywa.*

9. Uma zikhona, yiziphi izindlela ozisebenzisayo ukulwisana nalezo zingqinamba?

- *Ngingekho ngasho ukuthi niyazlwela mna uqobo. Ngumdali wezinto zonke okunguye owangibeka kulesi simo futhi namanje okunguye ongihlangayo. Ukubhekisa kuye konke. Ngokubona izimo engiba ngaphansi kwazo, njalo uyele angitakule.*
- *Ukwazana nokusebenzisana nabanye abantu njengalaba bama support group kuyisu elihle elikhombise ukuthi liyasebenza. Lapho phela uxoxa nabantu*

*eninezinkinga ezifanayo nabo – ngakho kuba lula ukuzixazulula. Abane babo bagcina sebefana nomndeni wakho wangempela.*