

EXPLORING THE EXPERIENCES OF MOTHERS AFTER PARTICIPATING IN A MOTHER-CHILD INTERACTION INTERVENTION, WITHIN AN HIV CONTEXT

by

ANASTASIA ANTONIADES SAVOPOULOS

Submitted in fulfilment of the requirements for the degree of

Master of Arts in Counselling Psychology

In the Faculty of Humanities

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SUPERVISOR: PROF M J VISSER

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When the music changes, so does the dance.

- African Proverb -





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SUMMARY

This research was conducted as part of the formative evaluation of a mother-child interaction intervention, which was incorporated into the Kgolo Mmogo pilot study at the Kalafong Hospital in Tshwane (South Africa). The purpose of the intervention was to encourage the development of parenting skills and to improve mother-child relationships within an HIV context over a six-month period. By promoting more effective interaction between mother and child, child resilience could be enhanced and children could learn the necessary coping skills that would help them deal with the challenges posed by HIV and other life events.

The aim of the study was to generate a systemic understanding of families affected by HIV/AIDS. The study explored (1) the effect of HIV on family interaction and (2) the effect of the mother-child interaction intervention on family interaction from the perspective of HIV-infected mothers. The theoretical framework chosen for the study was of a systemic nature and the standpoints, as set out by the Milan family therapy team, were implemented. Ten months after the intervention, four of the HIV-positive mothers who had participated in the intervention were interviewed and encouraged to share their experiences. Circular questions were employed in the interviews as a means of gathering data. A qualitative design was therefore the best option for this study.

The research findings of this study coincide with previous literature and research findings; thus, the findings of this study have been consolidated. The current study findings support the importance of bridging the distance that is created by HIV in family relations, particularly between mother and child. Newly-diagnosed mothers often become stuck in their own processes and distance themselves from others in order to make sense of their situation. The broader social stigmas associated with HIV/AIDS contribute further to the sense of isolation that HIV-positive women experience. Often, women perceive HIV to be a disruptive force in their relationships with their partners and children, which creates tension, secrets and uncertainty within the family. HIV-infected mothers generally feel that keeping secrets from their children protects them from being traumatized by the social stigmas surrounding HIV/AIDS. Some HIV-positive mothers also feel that an emotional distance will shield their children from the pain of losing their mother. Because they are grappling with many negative feelings, such as anger and frustration, many HIV-positive mothers resort to strict disciplinary measures and avoid spending time with their children. The children misinterpret their mother's behaviour and react in a manner that the mother perceives to be both disrespectful



and disobedient, thus creating a recurring cycle in which both mothers and children become stuck.

The participating mothers perceived the mother-child interaction intervention to focus on their emotional, physical, cognitive and behavioural needs as well as the needs of their children. The mothers experienced the intervention as having been particularly helpful to them and their children. They perceived themselves to be warmer, more supportive, more accepting and to have found meaning in their lives. In addition they felt that their children had begun to behave themselves and were also less avoidant of them. It enhanced their understanding of one another, and strengthened their bond so that they can depend on each other in times of difficulty.

Key Terms

HIV-positive mothers; effects of HIV; mother-child interaction; mother-child intervention; resilience; family; family structures; system; systemic perspective; first-order cybernetics; second-order cybernetics; case study; qualitative; circular questioning.

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CHAPTER 1 INTRODUCTION

1.1. INTRODUCTION

"The HIV/AIDS epidemic is causing a complex systemic change in human ecology. It is unleashing secondary impacts that have demographic and epidemiological consequences, which in turn create feedback loops into the dynamics of the epidemic itself" (Whiteside, 2008, p. 123).

As AIDS continues to ravage communities across the African continent, the future of many of these communities remains in question. Research has shown, that, as a result of the AIDS epidemic, many societies will undergo significant demographic changes: life expectancy will be shorter; gender ratios will vary; the number of orphans will increase and there will be a shift in population structures (Whiteside, 2008). The widespread prevalence of HIV and AIDS in Africa and in South Africa, in particular, has resulted in a huge number of families being affected. Family structure and dynamics have been dramatically impacted by the AIDS crisis. As a result, children are forced to grow up without their parents' support and care. Many children witness their parents getting sick and dying. Still others have never had the opportunity to get to know their parents, to have been held by them, or to have felt cared for by them. In addition, many parents, especially mothers, have not had the opportunity to experience their children's support and care.

According to the latest report on the global HIV/AIDS epidemic (United Nations Programme on HIV/AIDS [UNAIDS], 2008), the ratio of people living with HIV to those living without HIV, has stabilized since 2000, however, the total number of people infected with HIV has increased progressively as a result of new infections which occur each year, and because new infections still outnumber AIDS deaths. In 2007, it was estimated that 33 million people worldwide were living with HIV. This figure also included 2.7 million people who had been newly infected. A disproportionately high number of HIV-infected individuals live in Southern Africa. Sixty-seven per cent of all people living with HIV worldwide, and 60% of women infected with HIV reside in this region.

More than half of all adults living with HIV in Southern Africa are women. In South Africa, in particular, there are twice as many infected women between the ages of 15 and 24, as there



are infected males in the same age range. It is estimated that for every 12 to 13 South African women that are currently infected, there are ten infected men (Walker, Reid & Cornell, 2004). "Girls and women are disproportionately vulnerable to HIV. Their physiological susceptibility – at least 2 to 4 times greater than men's – is compounded by social, cultural, economic and legal forms of discrimination" (United Nations Population Fund [UNFPA], 2002, p. 2). It is therefore vital that the effects of the AIDS epidemic on women be viewed holistically, taking into account the biological, psychological and social context, as well as the power dynamics that inform sexual behaviour, sexual relationships and gender inequalities (Walker et al., 2004).

Despite the numerous efforts made to curb the pandemic, AIDS continues to spread, and many children are now affected by this disease. Sub-Saharan Africa is home to almost 90% of children who are directly affected by the epidemic. Some children are infected with the disease and living with the consequences of HIV (IRIN PlusNews, 2007b; Shetty & Powell, 2003), while others are forced to witness the corollary of HIV and AIDS on their chronically ill parents or relatives (IRIN PlusNews, 2007b; United Nations Children's Fund [UNICEF], 2006). These children are often expected to take on household and care-giving responsibilities especially when their households are experiencing greater economic challenges brought on by the disease (Booysen & Bachman, 2002). It is not uncommon for these children to forgo their studies and start working to support their families. As if this weren't traumatic enough, children are often stigmatized and discriminated against by their peers, relatives, educators and other community members because of their association with a person infected with HIV/AIDS. Worst of all, children can also face the possibility of losing one or both of their parents to AIDS-related illness (IRIN PlusNews, 2007b; UNICEF, 2006).

Research conducted in ninety-three third-world countries, indicated that over 140 million children under the age of 18 had lost either one or both of their parents by the end of 2004 as a result of AIDS and other causes – 43 million of these children originated in sub-Saharan Africa. Research also shows that the orphan population will increase in the next decade, as more HIV-positive parents become ill and die from AIDS despite the intensive scale up of AIDS treatment (United Nations Programme on HIV/AIDS [UNAIDS], United Nations Children's Fund [UNICEF], United States Agency for International Development [USAIDS], 2004).

"The way the disease has spread shows the fractures and inequalities of our society; it also shows how interconnected we are. HIV emerged in Africa and spread across the globe in less than ten years" (Whiteside, 2008, p. 124). It is for this reason that family members need



to stand together against the fight against HIV/AIDS. The family is the nucleus of the social context. It forms one of the most fundamental building blocks of society, binding innumerable communities of complex interdependence together (Barolsky, 2003).

Berk (2000) stipulates that, not only do families need to promote the survival of their own members, but, as a family unit, they need to execute the following essential functions in order to ensure the survival of a society:

- Reproduction ensuring a legacy by replacing the dying members.
- Economic services distribution of produced goods and services.
- Social order procedures must be in place to eliminate conflict and maintain orderly conduct.
- Socialization training the young members so that they can become competent, participating members of society.
- Emotional support measures must be outlined for uniting individuals, dealing with emotional crises, and nurturing a sense of commitment and purpose in each person.

The institution of the family as an active network of care could function as one of the most vital social resources in South Africa, as it could help curb the effects of the HIV epidemic. However, HIV/AIDS also acts as a profound test of integrity and durability of the family. Families are challenged when HIV is introduced into the home by an infected member. For example, the infidelity of a partner could lead to the break-up of a marriage; the family may have to deal with the death of a parent or a child or children could be orphaned. These challenges place immense strain on the family's ability to perform as an agent of socialization, economic support, nurturing and care (Barolsky, 2003).

Mothers and children are active participants in families, thus it is important to strengthen mother-child relationships so that the family members are able to rely on each other in times of adversity, in an HIV/AIDS context. Such interaction can encourage the children to develop coping skills that they can use when they have to fend for themselves and their younger siblings, should the mother become ill or die. Thus, maintaining a parent's health and enhancing the relationship between mother and child could have a significant beneficial effect on a child, allowing the child to mature normally.



1.2. BACKGROUND TO THE STUDY

The present study forms part of a larger study, the Kgolo Mmogo project which is a five year project. One of the goals of the larger project is to test the effectiveness of an intervention that is specifically focused on promoting resilience and improving the adaptive functioning of young children, between the ages of six and ten years, of HIV-infected mothers. The Kgolo Mmogo project presents a support programme which requires the mothers to attend weekly support groups with other HIV-positive women over a six month period. Each session covers a specific topic, such as effective parenting, problem solving, disclosure, etc. Their children (aged six to ten) participate in similar sessions with other children. The last ten sessions are joint sessions where the mothers and their children are given the opportunity to engage in activities together.

The intervention will eventually be implemented by a non-governmental organization (NGO) which will use trained volunteers to implement the programme. If proven to be effective, this programme could be replicated in resource-poor communities in South Africa and other countries.

The present research will focus on the outcome of the mother-child-interaction after participating in this intervention as part of a formative evaluation of the intervention.

1.3. AIMS OF THE STUDY

The purpose of this study is twofold: (1) to explore how HIV-infected mothers experience HIV to impact on their family relationships and (2) to investigate the same mothers' experience of their relationship with their children after participating in a mother-child intervention.

The researcher will use circular questioning to explore how the mothers perceive the influence of the intervention on their relationship with their children. The research will focus on whether they feel that the intervention facilitated closer relationships between themselves and their children, and if they were more likely to identify each other's emotions and understand each other better. The research will also ascertain whether they are more supportive towards each other after the intervention. Thus, the focus of the research will be on the effectiveness of the intervention to help the mothers to redefine their family interaction.



The experience of HIV-positive mothers participating in a mother-child intervention is an important aspect of the evaluation of the programme in order to determine its effectiveness.

Furthermore, this study can elicit awareness about mothers and children in disadvantaged South African communities that are infected and affected by HIV/AIDS. This research can also play a profound role in educating health care workers and enriching their understanding of the impact that HIV has on families in the South African context.

1.4. NATURE OF THE STUDY

The nature of the study is systemic as it follows the viewpoints set out by Selvini-Palazzoli, Boscolo, Cecchin and Prata (1978) who are also known as the Milan family therapy team. The theoretical concepts implemented by the Milan team draw from systems theory, cybernetics and information theory (Tomm, 1984a).

Systems theorists are less concerned with discovering the cause of a problem, but rather see people in mutual interaction and /or reciprocal causality. Therefore, human beings are constantly in a relationship with each other so that each person interacts and jointly influences the other (Becvar & Becvar, 2002; Keeney, 1983; Watzlawick, Beavin & Jackson, 1967). A basic rule underpinning systems theory is that the whole is greater than the sum of the parts. Therefore two individuals plus their interaction equals three. If more individuals are involved in a system, it means that there is potential for a greater number of relationships (Becvar & Becvar, 2002). This principle of relationship implies that if there is a change in one part of the system, the whole system is affected (Bateson, 1979; Efran & Lukens, 1985; Keeney, 1983; Watzlawick et al., 1967).

Keeney (1983) suggests that we cannot attempt to understand a system by dividing it into its parts, nor can we view a person as being separate form his or her surroundings. Rather, the person is viewed in context, so that the relationships that exist between parts become important to understand differences. Furthermore, Keeney (1983) stipulates that we are not surrounded in a world of opposition, rather in a realm of both/and dichotomies. Therefore, it could be suggested that an understanding of both first and second-order cybernetics may be a helpful tool in understanding the processes of human interaction. The one cannot exist without, nor be replaced by the other (Becvar & Becvar, 2002).

In this study, four mothers will be interviewed by incorporating the technique of circular questioning, as set out by the Milan team (Selvini-Palazzoli et al., 1978). The questioning



will be designed to ensure that a holistic understanding of how HIV impacts on the family system is gained. In addition, the influence of the intervention on the mother-child relationship will be explored to determine its effectiveness. The mothers chosen for the study are voluntary participants and have given their full consent.

1.5. OVERVIEW OF THE STUDY

This study consists of six interdependent chapters which all work together to bring this study together as a whole. **Chapter 1** introduces the reader to the study at hand and provides a brief outline of the background of the study. **Chapter 2** offers an overview of the AIDS epidemic, and highlights literature focused on the physiological, psychological and social effects of HIV/AIDS on women; the effects of HIV/AIDS on mother-child relationships and the psychological effects on children living with HIV-positive parents. A detailed explanation of the theoretical perspective used in this study will be provided in **Chapter 3**. **Chapter 4** follows with a description of the methodology used in this study. This chapter also includes the research process and the ethical procedures that need to be considered. In **Chapter 5**, a detailed description of the findings will be presented, followed by an overall discussion of these findings in **Chapter 6**. Finally, a conclusion to the study with a critical evaluation and recommendations for further research will be presented in **Chapter 7**.



CHAPTER 2 LITERATURE REVIEW

2.1. INTRODUCTION

The aim of this chapter is to highlight the main concepts that form the basis of this study through a review of existing literature. First, a definition of HIV and AIDS is given, and this is followed by a global overview of the AIDS epidemic. Literature which focuses on the physiological, psychological and social effects of HIV/AIDS on women, and on how HIV/AIDS may impact on mother-child relationships is then reviewed. The AIDS epidemic and its effects on children, specifically the psychosocial effects on children living with terminally ill parents, is explored. The concept of resilience in children as a coping mechanism is also discussed.

2.2. WHAT IS HIV AND AIDS?

2.2.1. HIV

Human Immunodeficiency Virus (HIV) belongs to the group of viruses known as lentiviruses, meaning "slow-acting". Lentiviruses produce diseases that develop over long periods of time; many of these diseases affect the immune system and brain of human beings (Whiteside, 2008). HIV is also a retrovirus. The prefix "retro" denotes that the virus does the opposite of what other viruses do. The typical genetic information transcription in cells is from DNA (deoxyribonucleic acid) to RNA (ribonucleic acid) to proteins. Unlike other viruses, the information transcriptions of retroviruses are contained in the RNA (Van Dyk, 2008).

The HI virus is spherical; it measures 0.0001 mm in diameter and consists of an inner matrix of protein called the core. The virus's genetic material (RNA) and several enzymes are stored within the core. The outer layer of the virus is surrounded by two proteins, namely glycoproteins, which are projected on its surface. These proteins perform a vital role in the initial phase of infection and in the production of antibodies which neutralize the virus. Because it is a virus, HIV can only reproduce inside a living cell that it has purposefully parasitized for its own benefit. The virus gains entry to the host cells by attaching itself to the CD-4 receptor. By directly attacking the CD-4 and T cells (the defensive cells of the immune system) the HI virus becomes extremely dangerous as the uninfected T cells lose their



immune capacity and die, resulting in immunodeficiency (Van Dyk, 2008; Zeller & Swanson, 2000).

HIV reproduces within these cells by producing more virus particles. This is achieved by converting viral RNA into DNA in the cell, with the assistance of an enzyme called reverse transcriptase. Afterwards, multiple RNA copies are manufactured. The conversion from RNA to DNA and back to RNA is significant as this process hinders the combating of HIV. Each time this process occurs there is the potential for error and the possibility of the virus mutating, as reverse transcriptase lacks the normal "proofreading" that occurs in DNA replication. Subsequent to their formation, these copies, or virus particles, will cause the cell to rupture. The cell is effectively destroyed, and the virus particles go on to infect other cells. Furthermore, when the virus mutates it "outwits" both biological and technological (drug treatment) human responses, consequently, it becomes extremely difficult for the body to rid itself of the virus (Whiteside, 2008).

2.2.2. AIDS

AIDS (Acquired Immune Deficiency Syndrome) is an acquired disease, meaning that it is not inherited but rather caused by the HI virus which enters the body from an external source. Once it has entered the body, it then attacks the immune system so that it becomes weak and unable to defend itself against new and passing infections and disease (Van Dyk, 2008). Lashley (2000) states that AIDS is generally defined as "a specific group of diseases or conditions that are indicative of severe immunosuppression related to infection with HIV" (p.2). Thus, strictly speaking, AIDS is not a disease and can be more accurately defined as a "syndrome of opportunistic diseases, infections and certain cancers – each or all of which has the ability to kill the infected person in the final stages of the disease" (Van Dyk, 2008, p.4).

Opportunistic diseases produce micro-organisms that are not normally pathogenic towards healthy immune systems. However, in systems where the HI virus is present and inhibiting, the body is successfully attacked (Van Dyk, 2008).

2.3. A GLOBAL OVERVIEW OF THE AIDS EPIDEMIC

Though there has been tremendous progress in the response to HIV since AIDS was discovered in 1981, HIV still remains a global health crisis of unprecedented proportions. At present, it is estimated that there are 33 million people worldwide living with HIV. In the last



27 years, the HIV pandemic has caused an estimated 25 million deaths across the globe, and has generated significant demographic changes in the most heavily affected countries, including Kenya, Rwanda, Uganda and Zimbabwe. In 2007, it was estimated that 2.7 million people were newly infected and approximately 2.0 million had died from the disease worldwide. Collectively, these deaths represent an immense loss of human potential. Individually, each is aligned with enduring trauma in households and communities (UNAIDS, 2008).

According to UNAIDS (2008), Southern Africa continues to seize a disproportionate segment of the global burden of HIV; in 2007, 35% of HIV infections and 38% of AIDS deaths occurred in this region. In total, 67% of all people living with HIV worldwide and 60% of all global women infected with HIV reside in sub-Saharan Africa (see Figure 1). Furthermore, approximately 370 000 children aged 0 to15 years became infected with HIV in the same year. The global number of children younger than 15 years living with HIV increased from 1.6 million in 2001 to 2.0 million in 2007 (see Figure 2). Sub-Saharan Africa is home to almost 90% of these children.

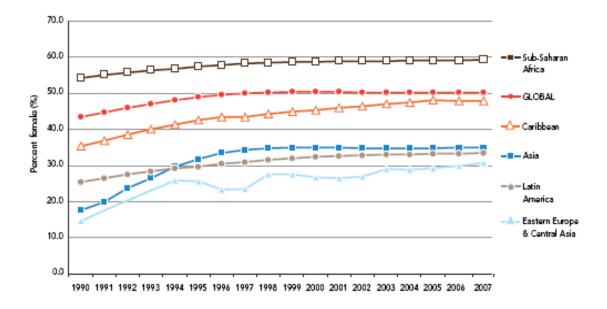


Figure 1: Percentage of female adults (15+) living with HIV, 1990-2007



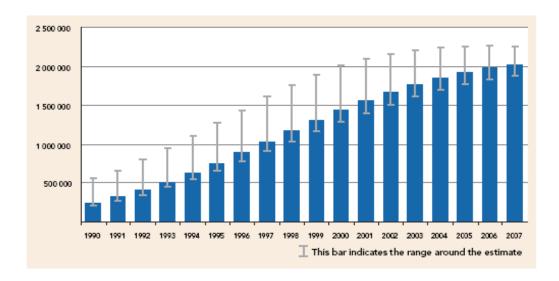


Figure 2: Global number of children living with HIV, 1990-2007

In the 2008 report on the global AIDS epidemic, the outlook is somewhat more optimistic. In some countries in Asia, Latin America and sub-Saharan Africa, the HIV incidence rate (the annual number of new HIV infections) and the estimated rate of AIDS deaths are declining. The annual number of new HIV infections has dropped by 300 000 in the past six years, partly due to the substantial increase in access to antiretroviral medication in areas where resources are scarce. Since the peak of the HIV incident rate in the late 1990s, the percentage of HIV-infected individuals between the ages of 15 and 49 has stabilized in many countries, including South Africa. Prevention programmes have been associated in playing a vital role in altering some sexual behaviour patterns that placed people at risk of contracting the virus (National Department of Health, 2008; UNAIDS, 2008).

The primary source of HIV data in South Africa is obtained from surveying pregnant women who visit antenatal clinics (ANC). The collection of such data assists in the monitoring of HIV trends and provides the basis for HIV estimates in the general population of South Africa (National Department of Health, 2008). The 2007 National HIV and Syphilis Antenatal Prevalence Survey indicates that South Africa has made some significant strides in the effort to curb the HIV epidemic.

The results from this epidemiological surveillance are the first to compare the impact of HIV infection in various districts over two consecutive years. The findings suggest that, because different virus strains are being circulated in South Africa, the epidemic is progressing at a different pace in the various provinces. The findings also show that HIV infection is on a downward trend, though still exceptionally high, as depicted in Table 1 below.



Province	HIV pos. 95% CI	HIV pos. 95% CI	HIV pos. 95% CI
	2005	2006	2007
KwaZulu-Natal	39.1 (36.8 - 41.4)	39.1 (37.5 - 40.7)	37.4 (35.0 - 39.8)
Mpumalanga	34.8 (31.0 - 38.5)	32.1 (29.8 - 34.4)	32.0 (29.2 – 34.9)
Free State	30.3 (26.9 - 33.6)	31.1 (29.2 - 33.1)	33.5 (28.3 - 39.1)
Gauteng	32.4 (30.6 - 34.3)	30.8 (29.6 - 32.1)	30.3 (29.9 – 32.8)
North West	31.8 (28.4 - 35.2)	29.0 (26.9 - 31.1)	29.0 (24.8 – 33.5)
Eastern Cape	29.5 (26.4 - 32.5)	28.6 (26.8 - 30.4)	26.0 (24.0 - 28.1)
Limpopo	21.5 (18.5 - 24.6)	20.6 (18.9 - 22.3)	18.5 (16.7- 20.4)
Northern Cape	18.5 (14.6 - 22.4)	15.6 (12.7 - 18.5)	16.1 (13.9 – 18.7)
Western Cape	15.7 (11.3 - 20.1)	15.1 (11.6 - 18.7)	12.6 (10.1 – 15.6)
National	30.2 (29.1 - 31.2)	29.1 (28.3 - 29.9)	28.0 (26.9 – 29.1)

N.B. The 95% CI was used because statistically the true estimated value falls within the two confidence limits and therefore assures us that there is 95% certainty that the estimated value is not by chance.

Table 1: Provincial HIV prevalence estimates among South African antenatal clinic attendees, 2005-2007

The same survey demonstrated that HIV prevalence amongst younger women (15-25 years) continues to show a significant decline, suggesting that intervention programmes that were implemented have had a profound impact on these women. The same cannot be said of older women - there has been no reduction in the incidence of HIV in women in older age groups (National Department of Health, 2008).

2.4. THE EFFECTS OF HIV/AIDS ON WOMEN

South African research has demonstrated that females are more vulnerable and susceptible to HIV infection than males.

Curbing HIV transmission does not only depend on biological determinants such as scientific interventions, male circumcision and the administration of antiretroviral medication, but also on changing behaviours and perceptions. Both biological and behavioural aspects are shaped by the culture, politics and economics that bind communities and societies together. These factors are crucial, and the most important are gender relations and income equality. The fundamental issue that needs to be focused on is how people perceive each other and how they behave towards one another (Whiteside, 2008).

The following section focuses on literature which highlights the difficulties women living with HIV experience, including the impact of the virus on their lives and on their relationships with their children.



2.4.1. The physiological effects of HIV infection on women

On the whole HIV/AIDS infection follows the same pattern in men and women. Women, however, are more likely to become infected with HIV than men, owing to their biological makeup. The risk of contracting the HI virus during unprotected sexual intercourse is two to four times greater for females than it is for males (World Health Organization [WHO], 2000; Women's International News Network, 2002).

The main reason why women are more vulnerable to HIV infections is because they are exposed to semen for a long period of time during vaginal intercourse. HIV concentration is generally higher in semen than it is in the female's sexual secretions. Also, semen remains in the female body for a few hours, whereas men are exposed to the women's fluids for a short period of time. Another important point is that the surface area of the female genital tract is much larger than that of the male, so women are exposed to greater quantities of sexual fluids (Van Dyk, 2008; Whiteside, 2008). Thus, the transmission of sexual viruses from a man to woman is several times more efficient than in the contrary manner (Patz, Mazin & Zacarias, 2000).

Women who are exposed to violent sex or rape, genital mutilation (female circumcision), "dry sex" (performed by African women as a sign of faithfulness) and anal sex can experience lacerations and bleeding which heighten the risk of HIV transmission (Van Dyk, 2008; Whiteside, 2008).

2.4.2. The psychosocial impact on HIV-positive women

HIV individuals experience a range of negative psychological responses to their condition (Adinolfi, 2000). In cross-sectional studies, conducted at the Tygerberg Hospital in Cape Town, South Africa, the psychological responses associated with HIV among black African women within their first year of diagnosis was explored. The baseline results indicated that the most frequent diagnosis was major depression (38.1%) followed by dysthymic disorder (22.9%). The author concluded that an HIV or AIDS diagnosis exacerbated the premorbid state of 19% of the participants who had been previously diagnosed with depression; 11.4% of the women were a suicide risk, 19% met the clinical diagnoses for post-traumatic stress disorder and 6.7% were diagnosed with generalized anxiety disorder (Olley, 2006).

More recently, a study (using narrative data analysis) was carried out on five poor HIV infected South African women, the purpose of which was to explore whether their lives were



predominated by chaos, loss and disruption. The findings indicated that some disruption was caused by the women's initial diagnosis. However, the women only became preoccupied with HIV when they were actively ill and not receiving antiretroviral medication. In these cases, a shift in their wellbeing was noted over time. The women made use of "denial-based coping strategies that kept HIV and chaos marginalised. Competing narratives concerned with poverty were typically dominated and served as a constant, through which women's experiences were filtered" (Brandt, 2008, p. 1). Brandt (2008) advocates that effective health care for poor HIV-positive women, should encompass a holistic approach that focuses on women's mental health needs and the alleviation of poverty.

Coleman (2003) states that individuals newly diagnosed with HIV are often in crises and tend to feel overwhelmed with emotions of fear and anger. Even though "women do not react uniformly to a positive diagnosis there are some commonalities in their expressions" (Lambert, 2004, p. 4). Many describe their initial reaction to their own or to a family member's diagnosis to be; shock, disbelief, anger, confusion (Im-em & Phuangsaichi, 1999, as cited in Im-em & Suwannarat, 2002), fear of death and anxiety about how others would respond to them if they were to find out (Feldman, Manchester & Maposphere, 2002). Other themes that are common among women who are informed of their seropositivity are feelings of guilt, hopelessness, intense sadness or depression, alienation (Coleman, 2003; Couvaras et al., 1994), suicidal thoughts and escalation of substance abuse (Stevens & Hildebrandt, 2004). Most of these women gradually accept their HIV status; however they may continue to feel guilty and intensely sad about their children's future. They may feel responsible for infecting them, or guilty that they will leave them behind to struggle and suffer when they die (Mdlalose, 2006).

A description will be given of specific common reactions to HIV.

2.4.2.1. Shock and denial

Initially the first reaction to a loss, be it death or loss of health, is often shock followed by denial (Kübler-Ross, 1969). Women experience great difficulty in accepting their seropositive diagnosis (Mokhoka, 2000). Many are numbed by the news and experience a temporary, defensive refusal to accept reality entering a state of denial, especially when the news is unexpected (Im-em & Phuangsaichi, 1999, cited in Im-em & Suwannarat, 2002; Weiss, 1988). Denial often gives people the time they need to gather their thoughts and the strength to deal with the news. However, it may become a problem if the person's denial leads to destructive behaviour (Van Dyk, 2008).



Feldman et al. (2002) state that prior knowledge about HIV or lack thereof, is associated with the degree of shock a woman may present. People in this stage may present with a lack of affect and have difficulty engaging emotionally with others (Kübler Ross, 1969), on the one side of the continuum, to extreme emotion, such as excessive crying, aggressive behaviour and withdrawing from others, on the other side (Miller, 1987). Typically individuals experiencing shock report feelings of confusion, lack of concentration and not being able to focus on any one thing for long periods of time (Miller, 1987).

2.4.2.2. Anger

Individuals normally react by trying to undo their loss (Weiss, 1988) even though they are aware that there is no cure for AIDS (Im-em & Phuangsaichi, 1999, as cited in Im-em & Suwannarat, 2002). Anger is a natural response when individuals are diagnosed with HIV. Individuals may experience emotional torment about the manner in which they contracted the virus or feel very angry that they did not know that they were infected (Van Dyk, 2008). The type of relationship a woman has with the person who infected her can determine whether or not she verbalizes and admits her feelings of anger (Mokhoka, 2000). The individual will feel anger towards the person who infected her, as well as anger at herself for her indiscretions. There might also be anger directed at the people closest to her, and at society's reaction of hostility and indifference (Van Dyk, 2008). "Inwardly directed anger may manifest as self-blame, self-destructive behaviour or suicidal impulses or intention" (Van Dyk, 2008, p. 269).

Often many women are in the process of coming to terms with their diagnosis when they are confronted with the death of a partner or child (Lambert, 2004). Therefore, a grieving widow may express her anger at God for allowing this to happen to her or she may resent the deceased person for dying and leaving her. The bereaved may view her feelings to be inappropriate, thus, she may redirect these emotions at others, for example, healthcare professionals (Van Dyk, 2008).

It becomes even more complicated when a faithful partner discovers her partner's infidelity through her seropositive diagnosis. Feelings of double betrayal and emotional outrage are often experienced by women when they discover that their partners are aware of their status and that they have concealed it from them (Feldman et al., 2002).

2.4.2.3. Shame and guilt

Lambert (2004) states that shame originates from two main sources, one being self-blame and criticism from the infected person, and the other from the stigmatization and blame originating from the broader social sphere in which the individual resides.



People living with HIV often feel guilt and self-reproach for having contracted HIV, and may even feel responsible for having infected their partners and children. The behaviour that caused them to become infected also burdens them. These feelings can derive from a person's unresolved conflict pertaining to issues such as sexuality, homosexuality (Van Dyk, 2008), promiscuity, rape, prostitution and drug misuse (Whiteside, 2008).

Disclosing one's seropositive status normally requires one to also reveal some personal information pertaining to their sexual behaviour and preferences (Van Dyk, 2008). Such information may distance those closest to the infected, who may in turn be the first to discriminate against them. Because of the stigma related to HIV, the source of the infection is often associated with negative connotations that help enforce shame on an individual. Having HIV is often associated with being unclean, infected, contagious and difficult to live with. Any association with the disease, even if they are not infected themselves, is perceived as shameful (Salmon, 2001). In a qualitative study based on experiences of HIV/AIDS diagnosis, disclosure and stigma in an urban informal settlement in the Cape Peninsula, participants mentioned that community members were afraid to become involved in AIDS activism in case they were labelled and stigmatized as HIV-positive themselves (Khan, 2004). "Stigma and blame is further compounded because many of the behaviours that lead to HIV transmission are circumscribed by society" (Whiteside, 2008, p. 118).

People living with HIV and people perceived to be living with HIV, internalize this stigma resulting in various negative outcomes such as isolating themselves from their friends, families and other social networks. Furthermore, internalized stigma has been associated with emotional distress, such as depression, high risk behaviour and deterioration in health status (Eba, 2007).

Another important aspect that must be taken into consideration is religion. Some religions view AIDS with punishment for sin. Many people living with HIV may feel that they are being penalized for bad behaviour or an immoral lifestyle. Such beliefs may lead to negative feelings such as low self esteem, depression (Wiley, 2003) guilt and shame.

In a South African study, incorporating a Social Constructionist and Psychoanalytic theory, the findings indicated that women draw on negative social discourse pertaining to HIV which they internalized and incorporated into their identities. However, women do attempt to resist their stigmatized identity "by splitting off these bad representations and projecting them outside of themselves" (Rohleder & Gibson, 2005, p. 20).



2.4.2.4. Fear and uncertainty

When women are diagnosed with HIV, they initially feel distress and fear as they think of death immediately (Rohleder & Gibson, 2005). They fear their illness, becoming sick, being in pain, coming to terms with their own death, and the deaths of family members and friends who are infected (Lambert, 2004). Previous studies of family structures of women at risk for HIV have shown that these women are often the primary caregivers for their children. Many of these women are young and are terrified that their illness will rob them of their roles as caregivers and mothers. They also fear dying and leaving their children orphaned (Medscape General Medicine, 1999; Whiteside, 2008). Thus, the HIV-positive mother needs to deal with the daunting task of having to make surrogate child-care arrangements before she is rendered incapacitated (Medscape General Medicine, 1999). In addition, people living with HIV "are particularly afraid of being isolated, stigmatized and rejected" (Van Dyk, 2008, p. 267).

Women fear the stigma attached to HIV as they are often blamed for bringing HIV into their families (Esu-Williams, 2000; Feldman et al., 2002; Whiteside, 2008) and consequently they are often rejected by their partners, friends, relatives and particularly by their in-laws (Feldman et al., 2002; Salmon, 2001; Van Dyk, 2008). A community study was undertaken in Botswana and Zambia to explore men and women's perceptions of partners who tested positively. The consensus was that men would most likely abandon their HIV-positive partners, whereas women were expected to initially react with anger, and then accept their significant other, after he tested positive (Nyblade & Field, 2000).

Women may feel debilitated by their fears of being held responsible and may be criticized for bringing HIV into their relationships, thus many opt not to seek appropriate care and consequently isolate themselves (Khan, 2004; Rohleder & Gibson, 2005; Salmon, 2001). A South African study found, that, HIV-affected individuals avoid being stigmatized by engaging in concealment strategies, for example, grinding antiretroviral medication into powder and avoiding taking these drugs in the presence of others. These attempts to conceal the use of antiretroviral therapy may result in the individual taking inconsistent doses of medication – in the case of pregnant mothers, this could jeopardize the health of the unborn baby and, of course, of the mother (Mills, 2006).

In Botswana, health care professionals confirmed that women often sought medical attention when they were extremely ill and could no longer hide their symptoms. By this point, they were far beyond the optimal stage for drug intervention (IRIN PlusNews, 2006).



Khan (2004) argues that, it cannot be assumed that families will be supportive of an individual with HIV. In a qualitative exploration study conducted in the Cape Peninsula, findings indicated that disclosure to family members often resulted in rejection and isolation. The infected person's privacy was violated by family members who informed the community of the individual's status. It is interesting to note that more women disclose their HIV-positive status to their partners than men do. Very few men reveal their status to their female partners when they discover that they are HIV-positive; they normally only reveal their status when they are very ill (Feldman et al., 2002).

Several women interviewed by Amnesty International in South Africa said that they were unable to protect themselves against HIV infections, because they feared been beaten or forced to have sex by their husbands or partners. When they suggested using a condom or refused to have unprotected sex (Women's International News Network, 2008), their partners perceived these suggestions as a challenge to their authority (UNFPA, 2002). It is also not uncommon for threats to be directed at the HIV-infected woman's children as a means of taking revenge on their mother (Medscape General Medicine, 1999). Fear of violence or of being accused of unfaithfulness or immodesty (UNFPA, 2002) can inhibit women from learning and/or sharing their HIV status and accessing treatment (WHO, 2008; Women's International News Network, 2008). Furthermore, they feel powerless to negotiate safe sex and preventing infections, re-infections and transmitting HIV to their unborn children should they fall pregnant under these circumstances (Whiteside, 2008).

Research conducted with healthcare providers working within the HIV arena showed that, almost half of the providers had treated at least one female client who expressed fears of emotional and physical violence. Over one-fourth of these women had been exposed to physical violence after disclosing their seropositive diagnosis to their partner (Medscape General Medicine, 1999). Further evidence indicates that women who fear or experience violence are disempowered by their male partners and tend to give in to their demands (Women's International News Network, 2008; WHO, 2008). Maughan-Brown (2007) highlights extreme cases in South Africa of women living with HIV that have been physically assaulted and murdered after disclosing their status.

In addition, these fears prevent women from disclosing their seropositive status to their employers, partners and families as they are financially dependent upon them (Salmon, 2001; Van Dyk, 2008).

Van Dyk (2008) points out that, women may be afraid to disclose their status because they are afraid that:

- They will be asked by their in-laws to leave their husbands and consequently their financial security.
- They may embarrass their families and that their children will think less of them, especially if they are ridiculed by their peers.
- They will lose their relationships; that their partners will leave them and that they will never find another partner resulting in them being alone and lonely forever.
- They will be victimized and abused by their partners, family members and the community. Moreover, they will be cast out of their homes and their communities and be denied the ordinary privileges of social life.
- They will lose their dignity and being labelled "prostitutes".
- They will lose their jobs.
- They will feel guilty for infecting their partners and their children.
- They will have to engage in multiple disclosures such as revealing an HIV diagnosis and admitting that they have been raped.
- That they will lose medical assistance for themselves as well as for their children.

Fear is often sparked by feelings of uncertainty about one's future, and can lead to anxiety, hopelessness, depression and stress. Fear of uncertainty may inhibit people from dealing with their current situation and cause them to react in a manner that will help them regain their previous state of equilibrium or state of mind. An HIV-positive diagnosis triggers an alarm for a major health crisis, threatening one's stability, hopes, certainties, life plans, ambitions and day-to-day functioning. Such crises cause significant emotional stress, changes in attitudes or viewpoints and adaptive changes in personality. People living with HIV may experience personal growth from such experiences; however, it may also act as a catalyst for psychological and spiritual regression and deterioration (Van Dyk, 2008).

2.4.2.5. Stress and anxiety

Stress and anxiety are common reactions when an individual is first diagnosed with HIV. The infected individual continues to experience these symptoms while living with the disease (Adinolfi, 2000; Phillips, 2003; Van Dyk, 2008). Stress is triggered by the various life changes and demands that one experiences. These changes and demands are experienced uniquely by different people, thus, everyone's response varies. Positive stress may be perceived as a motivator, whereas negative stress can be overwhelming and burdensome.



The Walter Reed Army Medical Centre (n.d.) highlights that people react to stress physically (i.e. muscle tension, headaches, chest pain, upset stomach etc.), emotionally (i.e. anger, low self- esteem, depression, anxiety etc.) and behaviourally (i.e. substance abuse, sleep disturbances, change in appetite, memory loss etc.).

Phillips (2003) and the Walter Reed Army Medical Centre (n.d.) point out that people living with HIV may endure various stressful events in their lifetime that may pre-empt the risk of distress and anxiety. From the beginning, one experiences intense anxiety when undergoing an HIV test and even more distress and anxiety when a seropositive diagnosis is received. Often, while struggling to maintain their health or fighting an opportunistic infection, HIVinfected individuals may become apprehensive, especially when they are constantly fatigued due to insufficient rest, sleep or recreation. Experiencing impairment and a loss of functionality in bodily, social, occupational or other areas may also generate feelings of anxiety and distress. They may become frustrated with their treatment, for example, or they may experience intolerance or side- effects of antiretroviral medication or they may have to change medication in order to control their viral loads. Some antiretroviral medication can also induce anxiety in individuals. In addition, the fear of disclosure, discrimination and stigmatization may result in regular conflict in significant relationships, such as with spouses, family members, close friends or work colleagues. More specifically, they may be concerned with issues pertaining to intimacy, negotiating safe sex and/or needle usage. Often, when a close relative or loved one passes away, the surviving HIV-infected person is confronted with feelings of loss, as well as feelings of insecurity about their own lives. A previous history or genetic predisposition to anxiety disorder obviously heightens each stressful moment that is endured.

Ciambrone (2001) conducted a study on the relative impact of HIV/AIDS on thirty-seven women in a first world milieu. The outcomes revealed that these women did not consider HIV to be the most devastating event in their lives. In fact, they view violence, mother-child separation and drug misuse to be more disruptive. Several factors, including race, previous drug use, abuse histories, social support and diagnosis, were central to these women's differential assessment of HIV in relation to other disruptive events. In deduction, HIV itself was not perceived to be devastating but rather the implications surrounding the context of their social, economic and family consequences were considered distressing on their lives.

Cole, Kemeny and Taylor (1997, as cited in Van Dyk, 2008) report that many diseases are precipitated by, and aggravated by an interaction of social, psychological and biological factors. The psychological experiences and stressors accompanying an HIV diagnosis can



play a profound role in the rapid progression from HIV infection to AIDS, since constant and recurring stress can make one vulnerable to many diseases. Stress, itself, is not responsible for the infection or diseases but contributes to the decrease of immune functioning (Van Dyk, 2008). "In a stressful situation, the body responds by increasing the production of certain hormones causing changes in the heart rate, blood pressure, metabolism and physical activity" (Walter Reed Army Medical Centre, n.d.: Stress, p. 12).

2.4.2.6. Depression and suicide

Women who experience the loss of a loved one due to AIDS, fear dying themselves or are mourning the loss of their own health or that of their child's, often endure symptoms of depression, including: withdrawal, depressed mood, apathy, tearfulness, irritability, lack of concentration, increase or decrease in appetite, sleep disturbances and loss of interest in social, occupational and sexual activities (Van Dyk, 2008). Depression affects one's mind, mood, body and behaviour (Revolution Health Group, 2007) and may lead to suicide or suicidal ideation within the first six months after diagnosis and during the severely symptomatic stage of AIDS in the final phase of the disease (Cook, et al., 2004; Medscape General Medicine, 1999; Olley, 2006; Sherr, 1995).

The literature indicates a high correlation between HIV/AIDS infection and suicide. Viral infections can trigger persistent and progressive modifications in emotional and cognitive functioning (Kopnisky, Bao & Lin, 2007). Many factors can lead to suicidal thoughts and attempted suicide including: the manner in which the HIV testing was carried out; a lack of social support; inadequate coping strategies; deterioration of health and a feeling of controlling ones death as they are not able to control any other aspect of the illness (Pugh, 1995; Sherr, 1995). Psychiatric conditions, such as depression, anxiety, substance abuse, delirium and AIDS dementia may be precipitated by the HIV infection in vulnerable individuals (Kopnisky, Bao & Lin, 2007; Medscape General Medicine, 1999).

In developed countries, a higher level of depression has also been reported among women living with HIV and women perceived to be living with HIV, than amongst members of the general population (Eba, 2007; Morrison et al., 2002; Olley, 2006). A positive diagnosis can act as a catalyst for depression when women are experiencing issues with their partners or families. Psychological disorders, a profound sense of grief and loss connected to having the illness may also render these women more susceptible to psychosocial stress (Medscape General Medicine, 1999).



HIV seropositive women are four times more likely to suffer from major depressive disorder than in HIV seronegative women (Morrison et al., 2002). Cook et al. (2004) postulate that symptoms of major depression are significantly linked with a higher probability of AIDSrelated mortality. However, women who received psychiatric and psychological services as well as HAART (Highly Active Antiretroviral Therapy) regimens and non-HAART combination therapy, lessened their chances of mortality. Their findings indicated that women who had chronic depressive symptoms were twice more likely to die of AIDS-related causes than non depressed women or women with fewer depressive symptoms. Their results confirm the findings of Leserman (2003) who stated the elevated symptoms of depression are associated with immune system suppression - speeding up the progression process to AIDS. Psychosocial factors such as depression, stressful life events, low social support and denial coping are associated with decreases in the CD-4 cell count and declines in lymphocytes (Leserman, 2007). Moreover, elevated cortisol levels during stressful periods may affect HIV viral replication and certain immune system responses. Evidence indicates that severe life stressors combined with high glucocorticoid activity can lower circulating lymphocyte populations, modifying the immune system's defence against infection (Leserman et al., 2000).

Even though many factors may contribute to depression amongst people living with HIV, South African studies depict that internalised stigma contributes more to depression than any of the other factors (Eba, 2007).

2.4.2.7. Acceptance

After much grappling with the various issues pertaining to an HIV diagnosis, many HIV-positive individuals reach a stage where they realise that HIV infection is a manageable disease. Of course, this is only possible if the individual is dutifully taking HIV medication and receiving psychosocial support from family, friends and health professionals (Van Dyk, 2008).

It is only once these individuals have worked through the grieving process, come to terms with what they have lost and adapted to their new environments or circumstances, that they manage to reach a level of acceptance. A successful adjustment to the task of adaptation requires one to redefine their loss in a manner that incorporates the positive aspects of the loss (Van Dyk, 2008). Bowlby (1977, as cited in Van Dyk, 2008) posits that, people adapt to loss when they recognise a change in their circumstances and redefine their life goals.



Rohleder and Gibson (2005) found that HIV-positive women from a disadvantaged, black township in Cape Town demonstrated the ability to cope with HIV and the capacity to protect themselves from the consequence of HIV. The findings indicated that these women did internalize the negative connotations and stigmas attached to HIV, to the point where they became part of their identity. However, the women did not remain passive receivers of their stigmatized identities and resisted some of the ideas that others imposed on them. By rejecting these stigmatised identities and believing in themselves, they were able to assert their own situation as more admirable and employed strategies to protect themselves from the perceived threats of the illness and from discrimination and stigmatization. In order to protect themselves further from the stigmas of HIV/AIDS they would "normalise" their illness by referring to HIV as being "just like any other disease" (Rohleder & Gibson, 2005, p. 15).

Van Dyk (2008) states that counsellors can assist HIV-positive clients, to adapt to their new circumstances by using a problem-solving approach and equipping them with decision-making and coping skills. In this manner, the client is more empowered to solve her problems and cope with her anxiety. Sowell et al. (2000) stipulate that spiritual activities help alleviate HIV associated stressors, assisting HIV infected women to adjust to their circumstances and enjoy some quality of life.

Support from others and accurate information about HIV are crucial factors which contribute to personal acceptance of one's HIV status (Coleman, 2002). According to the 2008 UNAIDS global figures only 38% of all young women have accurate, comprehensive knowledge of HIV/AIDS. This indicates that the majority of women are not able to protect themselves effectively nor are they able to reach a level of acceptance. A woman, who has a partner with whom she can communicate openly, and who displays commitment to their relationship, is more likely to adjust to her new circumstances. She is also more likely to protect herself and her partner from further infections. Furthermore, partners that have been correctly educated about HIV are less likely to resort to violent behaviour (Feldman et al., 2002). In another South African study, the findings show that, community members who have been educated about HIV/AIDS, and have an understanding of the implications of HIV/AIDS for the affected family members, are more accepting and supportive of infected individuals (Khan, 2004).

Esu-Williams (2000) maintains that for women in Africa, their strength has been and remains, in working together, educating one another, sharing their experiences and supporting each other. In such supportive and cohesive communities personal acceptance is assimilated.



HIV-positive mothers can thus benefit from an intervention where information on HIV/AIDS is communicated. Such an intervention can also teach people living with HIV how to take physical and emotional care of themselves and their families, as in the case of the mother-child intervention that is being evaluated in the current study.

2.4.3. The contributing effects of female gender socialisation

Society and culture place a huge responsibility on women. Many African women still live in a patriarchal society, where they need to prove their worth by being married, having children and caring for their families. They are conditioned from a young age to believe that they are insignificant in comparison with the men in their families and communities. In such communities, women who are affected by HIV/AIDS are often not equipped to exert themselves and confront the denial of their fundamental rights, including, their right to own or inherit property; their parental right to their children; the right to financial independence (Esu-Williams, 2000); their rights to education, health care, reproduction, safety and protection (Gupta, 2005a; UNFPA, 2002). Poverty, low social status and lack of economic rights and opportunities increase young girls and women's vulnerability to HIV and stress.

Gupta (2006a) stipulates that in many third-world communities, women who have taken ill or whose husbands or fathers fall ill and die of AIDS, are faced with unstable and insecure financial situations. Often, they are evicted from their homes, lose their inheritance, possessions and livelihood because of "property grabbing" by relatives and community members who are fully aware that these women have no accessible legal means to recover possession of their property. In some developing countries of the world, it is illegal for a woman to own land or inherit land or housing. Disempowered by such economic situations, women and girls may see no alternative but to engage in risky behaviour, such as, prostitution and sexual deviance, in order to fend for themselves and their children. "In South Africa, black women generally occupy the lowest rungs on the hierarchy of social, economic and political power. Women are also the group most affected by HIV and AIDS" (Rohleder & Gibson, 2005, p. 3).

The unwritten rules created by society regarding gender differences play a profound role in the way stigma impacts on men and women (Gupta, 2001) and the way in which stigma is perceived by people living with HIV/AIDS (Maughan-Brown, 2007). The subordinate roles that society assigns to women exacerbate the HIV stigma and the experiences HIV-positive women encounter (Soskolne, 2003). France (2004, as cited in Almeleh, 2006) describes women to bear the brunt of gender moralistic judgements in her research investigating the



causes and experiences of stigma in Africa. France's findings depicts a common problem in all countries to be, that HIV-infected women are perceived to be promiscuous and blamed for the spread of HIV by their partners and families. Women tend to disclose their status whereas men hide their status and shift blame on to their female partners for introducing HIV into their relationships. If a woman is HIV-positive, she is accused of having infecting the man, however when a man is ill it is seen as an unfortunate stroke of luck and he is given sympathy and redeemed of his fault. France's findings concur with that of other researchers who found that a man's manhood is demonstrated by the many sexual partners that he has been with, however when a woman has many sexual partners she is perceived to be promiscuous, deviant and dirty (Shefer et al., 2002). Furthermore, women infected with sexually transmitted diseases, including HIV are stigmatized further as deviant, dirty, damaged and are viewed to be the source and infectors of such sexually transmitted diseases and HIV. Interestingly, 66% of women surveyed in Harare (Zimbabwe), Durban and Soweto (South Africa) reported having one sexual partner in their lifetime and 79% had abstained from sex until the age of 17. Yet 40% of all young women surveyed were HIVpositive (UNAIDS/WHO, 2005).

In many cultures, women are expected to be ignorant about sex and passive in sexual interactions. The traditional norm of preserving their virginity also places women in a difficult situation, for example, if a woman is sexually active or if she has been raped she may be fearful to ask for help. Thus, many women feel guilty and ashamed to express their sexual knowledge or negotiate safer sexual practices (Gupta, 2001). Men, on the other hand, have been socialised "to be sexually knowledgeable and experienced, to be virile and healthy, and may express sexual prowess to prove their manliness through casual and multiple partners (including sex workers), infidelity and dominance in sexual relations" (UNFPA, 2002, p. 1). Consequently many men are discouraged to seek health care or advice regarding sexually transmitted infections including HIV/AIDS (UNFPA, 2002).

Women have also been given the social responsibility of taking care of their family members' health and emotional wellbeing. Thus when women fall ill and depend on others to take care of them, they internalise this as having let their families down resulting in feelings of guilt and shame (WHO, 2000). In poor households and communities women and girls experience the devastating impact of HIV and AIDS more severely. In the majority of these households, women serve as the primary caretakers of the sick and dying, often at the expense of their own health. They often struggle to sustain an income and make ends meet as they are required to stay at home, thus they are prevented from maintaining a steady job. Often, they are forced to remove their children from school in order to obtain the extra labour that they



require, creating a persistent intergenerational cycle of deprivation and poverty (Gupta, 2006b).

When women are confronted with economic challenges, they are more susceptible to sexual trafficking, exploitation, "sugar daddies" and exchanging sex for money and necessary goods in order to alleviate financial burdens (Gupta; 2005a; UNFPA, 2002). Because they want to survive and fend for their children, women are less likely to negotiate condom usage and less likely to leave a relationship which they perceive to be risky. Once infected however, these women struggle to provide for their families (Gupta, 2005a), as they are then perceived by their clients and "sugar daddies" to be unfit and dirty when they are ill.

In South Africa, many AIDS-infected women living in poverty are caught in a difficult situation when they qualify for a state disability grant. They are confronted with the dilemma of maintaining their health with the use of antiretroviral medication versus obtaining money from the government when their CD-4 count is extremely low. Even though most people affected with AIDS would opt for antiretroviral treatment instead of the disability grant, the literature indicates that some individuals would prefer to die than to lose their grant. In the latter case, these individuals rely on the grant to provide for themselves and their families (LeClerc-Madlala, 2006).

In many poor households and in poor communities, child marriages are more prevalent. Girls, sometimes as young as ten years old, are married off to older men so that friendships and economic ties between families can be strengthened. These young brides often do not know their prospective husbands, which can create great anxiety. In many cases, they are also vulnerable to HIV infections as their husbands have usually had a number of sexual partners by the time they marry, thus increasing their chances of exposure to HIV. In many African cultures, including South Africa, the premium placed on having children often deters newly-weds from using condoms; consequently, young brides are at risk of contracting HIV (Gupta, 2005b; Women's International Network News, 2002). Furthermore, girls younger than 14 years of age are five times more likely to die giving birth, or during pregnancy, than young women in their twenties. In poor communities where there is a lack of health services, such as family planning clinics, child wives run the risk of experiencing complications during pregnancy (Gupta, 2005b).

Bride price, dowry or "lobolo" is required in some societies, including societies within South Africa. The prospective husband, or his family, must pay the father of the woman or girl he wants to marry. Once the bride price is paid, the woman cannot leave her husband



(Women's International Network News, 2002). Tradition forces women and young girls to stay in their marriages even if they are unhappy, and their husbands place them at risk of contracting HIV. Furthermore, women are assigned a submissive role in their relationships and are prohibited from protecting themselves during sexual intercourse as they are perceived as being "owned" by their husbands.

Another factor contributing to the vulnerability of women or girls, and the distress that they may encounter, is a lack of education (Gupta, 2005a; UNFPA, 2002). Girls are denied an education in some communities as this is seen as a waste of financial resources. "An investment in girls is seen as a lost investment because the girl leaves to join another home and her economic contributions are to that home" (Gupta, 2005b, p. 3). Globally, girls and women have lower education levels than men (Gupta, 2005a; UNFPA, 2002). Furthermore, there are fewer girls enrolled in school than boys, and more boys complete their studies than girls (Gupta, 2005a). Gupta (2005a) highlights studies conducted in Zambia and Kenya which convey that individuals who are better educated are less likely to become infected. Lower education levels correlate to a lack of HIV/AIDS knowledge, a lower rate of condom usage and minimal discussion regarding HIV prevention among partners.

2.4.4. The effects of HIV on motherhood as an important feminine ideal

Approximately 80% of HIV-positive women are of childbearing age (Craft, Delaney, Bautista & Serovich, 2007). The issue of motherhood in many cultures is an important feminine ideal, women are thus faced with a moral dilemma when they use barrier methods or engage in non-penetrative sex (Gupta, 2001). Many HIV-positive women with a procreative inclination are in a bind from the outset. On the one hand, they would like to give birth to a healthy baby, thus fulfilling their own desires and those of their partner's, as well as society's expectations. On the other hand, they are concerned about the social stigma associated with HIV. Evidence indicates that these women will often choose to fall pregnant even though they are HIV-positive in order to fulfil their desires to have a child as well as to portray that they are healthy. Despite the risks involved or the pain that disclosure might cause, these women still opt to have children (Craft et al. 2007). The pressure of having to fall pregnant, knowing that their partners or that they themselves are HIV-positive, makes the situation more stressful for women, as they are concerned about infecting themselves, their partners and their unborn child (Van Dyk, 2008; Whiteside, 2008). Furthermore, they need to deal with the issue of disclosure and stigma should they resist their cultural norms or seek medical attention (Rohleder & Gibson, 2005; WHO, 2008; Women's International News Network, 2008).



For these women, disclosing their status could mean that they lose their newborn babies to their partners or in-laws. They also run the risk of losing their partners, social support, financial security and homes (Gupta, 2006a; Van Dyk, 2008) and could even become victims of violence (Esu-Williams, 2000; Khan 2004; WHO, 2008; Women's International News Network, 2008) as they may be deemed unfit or deviant mothers and partners.

Women who discover their seropositive status while they are already pregnant experience extreme stress. The reason for this is that they are trying to come to terms with their own status, and needing to make decisions about their baby's health, at the same time (Lambert, 2004; Van Dyk, 2008). The situation can snowball when they need to disclose their status, as well as other personal information, to their partners, families and medical staff, as they run the risk of being "found out" (Coleman, 2003; Lambert, 2004; Van Dyk, 2008).

Craft et al. (2007) corroborates that woman with higher levels of personalized stigma and negative self-image, were more inclined to become pregnant by choice. They attribute this to their desire to have a child so that they can have someone to love or someone to love them back. They may also decide to fall pregnant so that they can appear healthy. On the contrary, women who experienced more external stigma were less likely to choose to get pregnant as they were concerned about how others would perceive them, and did not want to be labelled cruel, callous or deviant. Furthermore, it was found that 81% of women who were diagnosed whilst pregnant and 5.4% of women who became pregnant after they were diagnosed chose to terminate their pregnancies.

The issue of pregnancy does not end here for mothers. During pregnancy, the mother may be fortunate enough to obtain antiretroviral medication so that the possibility of transmission of the virus from mother to child is reduced. However, in many under-developed countries, medication is not available, thus increasing the risk of transmission of the HI virus to the child. Furthermore, pregnant women who do not take medication, run the risk of shortening their own lives at the expense of their children's. Once the child is born, the mother may not want to breast-feed. However, there is the possibility that she may be pressured into doing so by her partner, family and community, and refusal to breast-feed might result in her being rejected by her family (Lambert, 2004).

In addition, the mothers need to wait until their child's status is confirmed. Ninety-nine percent of infants with HIV are diagnosed within their first four months of life; for the mothers, this is a long wait. This waiting period may contribute to psychological and physiological distress for the mothers, as they are concerned about their infant's status (Shannon, 2005).



It is vital that these mothers learn to deal with their emotions and personal issues as their fears and concerns may restrain their interaction with their children. Consequently complicating their relationships with their children as their children could misinterpret their mother's behaviour (Miller & Murray, 1999).

2.5. THE IMPACT OF HIV/AIDS ON MOTHER-CHILD RELATIONSHIPS

Very few studies have investigated the impact of HIV/AIDS on mother-child relationships. The available literature shows that good mother-child relationships enhance psychosocial adjustment in children of HIV-infected mothers (Dutra et al., 2000; Forehand et al., 2002; Hough, Brumitt, Templine, Saltz & Mood, 2003; Kotchick et al., 1997). This section will focus on existing literature and aims to shed light on the potential effect HIV/AIDS can have on these dyads.

In a study investigating the development of infants of HIV-positive mothers, it was noted that, high parenting quality and consistency of primary caregivers contributed to positive developmental outcomes. It was also found that infants exposed to HIV presented with higher mental development, motor skills, language abilities and adaptive behaviour when parental care was consistent and positive, than when care-giving was inconsistent (Holditch-Davis et al., 2001).

Infants and toddlers are very demanding and many HIV infected mothers may not be able to give them the care and stimulation that they require due to their own lack of energy or poor health. Children may possibly miss out on important fundamental activates needed for physical and psychosocial wellbeing, and develop behavioural difficulties (Miller & Murray, 1999). AIDS-infected mothers in Uganda indicate that they are less likely to care for themselves adaptively; are significantly more depressed, express significantly less positive affect and were significantly less able to interact with their infants in comparison with non-infected mothers as shown on the Waters Attachment Q-set. This instrument was used to assess the quality of the infants' attachment with their mothers. It was ascertained that infants of infected mothers were significantly less securely attached in comparison to infants of non-infected mothers (Peterson, 1994).

Furthermore, after giving birth, HIV infected mothers are advised to bottle-feed rather than breast-feed. This process may prevent mothers from forming close physical and emotional bonds with their infants (Miller & Murray, 1999), however, studies have indicated that mother-



child bonds can still be formulated when mothers hold their babies close to their bodies while bottle-feeding in a manner that mimics the act of breast-feeding (Berk, 2000).

Kotchick et al. (1997) state that good quality mother-child relationship and the mother's monitoring of her children's activities, are central parenting factors that enhance the psychosocial functioning of children. In the aforementioned study, HIV-infected African American mothers living in inner cities conveyed poorer relationship quality with their children, and less monitoring of their children's activities than non-infected mothers. In an American study exploring the psychological adjustments of 60 seronegative ethnic children, (11 to 16 years old), who were living with their HIV-seropositive mothers, were compared with 108 children attending public school in the same community. The results confirmed that the children affected by HIV had greater difficulties in their relationships with their mothers. They also had poor social support and greater psychological dysfunction, than non-affected children. For the most part, these differences were attributed to the affected children's perception of more indifference and hostility in mother-child relationships; perception of lack of support from parents, peers, and educators, and having lower self-esteem than the children who were not affected by HIV. These results suggest that maternal HIV infection may disrupt effective parenting and psychological adjustment in children (Reyland, McMahon, Higgins-Delessandro & Luther, 2004).

Research regarding psychosocial and behavioural impact of a mother's HIV status on her uninfected children indicates that these children are extremely vulnerable and are at risk for not developing adequate psychosocial coping skills. In determining which factors are detrimental to the psychosocial adjustment of such children it was indicated that the following, in order of importance, were significant: HIV-associated stressors; maternal emotional distress; poor quality of parent-child relationship and a lack of child social support and child coping (Hough et al., 2003).

Forehand et al. (2002) compared the psychosocial adjustment of non-infected children of infected and non-infected mothers in a four-year study. In addition, they examined the differential changes and the role of parenting on the child's adjustment. Their findings indicate that, children of HIV-infected mothers presented with more symptoms of depression, than children of non-infected mothers. No differential changes regarding monitoring and relationship quality were reported from either the infected or non-infected mothers. However, in both groups, positive mother-child relationships were correlated to fewer adjustment difficulties. Furthermore, Jones, Foster, Zalot, Chester and King (2006, p. 409) stipulate that "a warm and supportive mother-child relationship afforded a more robust buffer against



externalizing difficulties for children who knew of their mother's illness than for children who did not".

HIV-infected mothers often find it challenging to provide adequately for their children's physical and emotional requirements when they themselves are grappling with feelings of guilt, shame, fear and anger associated with their diagnosis. In addition, their physical symptoms, such as fatigue, nausea, diarrhoea and side effects of potent medication may also complicate their relationships with their children. Despite these difficulties, HIV-positive mothers that are faced with death and terminal illness are more inclined to make future plans for their children than HIV-negative mothers are. Evidence indicates that spirituality impacts on future planning as well as on the emotional effects of death and dying (Westpheling, 1999).

Children affected by the adverse outcomes of HIV/AIDS could potentially benefit from an intervention focusing on promoting adaptive functioning and life skills that can be utilised in adverse circumstances, such as the intervention of the current study.

2.6. THE AIDS EPIDEMIC AND ITS EFFECTS ON CHILDREN

"Families are the most central and enduring influences in children's lives...The health and wellbeing of children is inextricably linked to their parents' physical, emotional and social health, social circumstances, and child-rearing practices. The rising incidence of behaviour problems among children attests to some families' inability to cope with the increasing stresses they are experiencing" (Schor, 2003, p. 1541). Thus, the psychological and social consequences of HIV/AIDS have given rise to various difficulties that may affect children of HIV/AIDS-infected parents. In this section, the research reviewed will illustrate these difficult areas that need to be taken into consideration when providing assistance to such families.

2.6.1. Infected children

Despite the numerous attempts that have been made in the last few years to stop the spread of AIDS, the disease continues to claim lives. Sadly, it is not only adults who have contracted the disease, but children too. Many of the world's HIV-infected children live in the Caribbean, South America and South-East Asia however the majority live in sub-Saharan Africa. Around 90% of all children living with HIV acquired the infection mainly due to mother-to-child transmission i.e. through pregnancy, birth or breast-feeding (UNAIDS, 2008).



Research indicates that one in three African newborns infected with HIV, die before the age of one, over half die before their second birthday and most children die before they are five years old (Newell et al., 2004) unless they receive antiretroviral treatment. In most regions of the world, including Africa, a decline in child mortality has been noted. However, in Southern Africa, the area most affected by HIV, the under-five mortality rate has increased due to the virus (Stanecki, 2004).

2.6.2. Orphaned children

By the end of 2007, 15 million children under 18 had lost one or both parents to AIDS worldwide. Approximately 12 million of these children are from sub-Saharan Africa. In countries badly affected by HIV/AIDS, such as Zambia and Botswana, it is estimated that 20% of children under 17 have been orphaned (UNAIDS, 2008). It is estimated that by 2010, 18 million African children will have been orphaned if nothing is done to curb the epidemic (UNICFEF, 2005). Even with the expansion of antiretroviral treatment access, the number of orphans will still be overwhelmingly high by 2015 (UNAIDS, 2008).

The consequences for the children and families of an ailing parent are numerous. "In the gathering crises of sickness and impoverishment, children can suffer emotional neglect before having to cope with the bereavement of one or both parents" (IRIN PlusNews, 2007a, p. 1). Traditionally, when families experience difficulties they would turn to their extended families as a place of refuge, however, the HIV/AIDS epidemic is placing southern African communities and families under immense pressure, for example, by exacerbating poverty and discrimination. Therefore, we can no longer assume that orphans will be financially provided for by family members. According to Monasch and Boerma (2004) double orphans (i.e. children who have lost both parents) are mainly cared for by the grandmothers in female-headed households faced with financial constraints. Such conditions are limiting these children from obtaining basic necessities such as food, clothing and schooling. Furthermore, evidence reveals that orphaned children are less likely to attend school and are also more likely than their peers to be malnourished (Bicego, Rustein & Johnson, 2003; Lindblade, Odiambo, Rosen & De Cook, 2003; Monasch & Boerma 2004; UNICEF, 2003). They are also more likely to suffer from anxiety and depression (UNICEF/UNAIDS/WHO, 2008).



2.6.3. The psychosocial effects of children living with HIV-infected parent/s

Children are directly affected in many ways by parental HIV, and are placed in a vulnerable position even before their parent passes away. The psychological effect on children cannot be simplified to that of the disease, as there is a preponderance of other risk factors which could affect children adversely. It is thus essential to examine the psychosocial contexts surrounding children in South African townships, as well as in other global communities severely affected by AIDS.

Poverty and unemployment in South Africa are extremely high – three out of every four children live in poverty (Streak, 2003). With no financial means, parents or caregivers have not been able to provide the appropriate schooling for these children. Households may experience greater poverty due to HIV/AIDS. A South African study indicated that the average per capita income in a family in which at least one person was HIV-infected, was less than half of the income in non-affected families (Booysen & Bachman, 2002). Thus, food consumption in an HIV/AIDS-affected family could drop significantly (UNICEF, 2003).

These children are placed in a vulnerable situation; they are often forced to stop attending school and are expected to take on the responsibilities of the breadwinner and caregiver at a young age (IRIN PlusNews, 2007b; Shetty & Powell, 2003). Girls are often denied an education, as they are typically taken out of school to assist in the home, and so that money can be saved for other resources (IRIN PlusNews, 2007b). Research indicates that in 2000, less than a quarter of children aged five to seven were attending early schooling, and children from HIV-affected families were less likely to be in school (Berry & Guthrie, 2003). As a consequence, these children could be exposed to work-related exploitation and violence, and the risk of child abuse; neglect and exploitation are heightened (Bauman & Germann, 2005; Berry & Guthrie, 2003; IRIN PlusNews, 2007b; Shetty & Powell, 2003). Sexual abuse is a fact of life for many of these children, and there is the distinct possibility that they too could become infected (Dawes, 2002).

Environmental stressors that can be identified as precipitating factors in the abuse of children, include financial problems, lower economic status; single working mothers; unemployment; poor housing (Spearly & Lauderdale, 1983); poverty and violence (Duncan & Brooks-Gunn, 1994; Hertzig, 1992). The majority of mothers are unmarried which may contribute further to their economic hardship and increase their parenting responsibilities (Pearlin & Johnson, 1977).



Children affected by HIV in their homes often witness a parent being ill and fear what will become of them once their parent passes away, as the likelihood of their second parent being infected with HIV and dying is probable. In addition to the trauma experienced within their families, children are often faced with the added trauma of stigmatization and discrimination which is enforced on them by their communities, peers, teachers and extended family (IRIN PlusNews, 2007b; UNICEF, 2006).

Even when children are not directly infected with HIV, they still bear the brunt of it as they are indirectly affected when their parents are infected. A parent's chronic and terminal illness may threaten a child's relationship with his/her parents. The child's constant need to feel love, trust and security may inhibit him/her from experiencing a normal childhood. Children may be exposed to stress in the family which contributes to feelings of anxiety, fear of abandonment and chronic insecurity. Often children resent their parent's illness and in return feel guilty and angry. Small children tend to doubt their ill parent's ability to provide for them, whereas, older children fear leaving their parent alone for long periods of time, for example, when they are at school. These fears may become intense resulting in generalised or separation anxiety. Research indicates that children benefit most when their life is structured and predictable, however, HIV/AIDS does not contribute to security but instead initiates feelings of uncertainty (Bauman & Germann, 2005).

Children with infected parents tend to encounter more disrupted routines and more periods of informal fostering with various caregivers, than children whose parents are not terminally ill (Bauman & Germann, 2005; Van Dyk, 2008). "In families where there is openness and the children are given as much security as possible, [the children] may be able to demonstrate something about resilience and continuity of family life" (Miller & Murray, 1999, p. 300). The concept of resilience will be discussed in section 2.8.

An important factor that should be highlighted is whether or not the child has been informed of his or her parent's HIV status. HIV-infected parents are frequently faced with the dilemma of having to disclose their status to their children, while trying to avoid discussing the implications of HIV and illness with family members. They are often unsure about what the appropriate age would be to tell their children about their status, and to explain to them the implications of their diagnoses and the source of the infection. Parents also fear that their children may reveal their secrets to others. A reluctance to clarify these aspects may distance parents from their children (Miller & Murray, 1999; Murphy, Steers & Dello Stritto, 2001).



Evidence from a study conducted on children whose parents had terminal cancer showed that children who had been told about their parents' diagnosis had significantly lower levels of anxiety than children who had not been informed of their parents' illness. Also, the uninformed children were seldom aware of the terminal nature of their parent's illness (Rosenheime & Reicher, 1985). Lewis (1995) stipulates that the child's age, circumstances and adaptive functioning contribute to their reaction to the terminal illness or death of a parent. Thus the responses were different among the different age groups, with uninformed children in the pre-adolescent years (ages 10-12) experiencing the most anxiety, followed by those in the latency age group (ages 6-9), with the adolescents being the least affected. Furthermore, studies have indicated that after a parent has passed away children tend to experience more internalizing symptoms such as, depression, anxiety, somatisation problems, post-traumatic stress and low self-esteem (Gersten, Beals & Kallgren, 1991; Stoppelbein & Greening, 2000; Worden 1996). These findings concur with those of Cluver and Gardner (2006) who investigated the wellbeing of children orphaned by AIDS in Cape Town. Their findings indicate that AIDS orphans present symptoms of post-traumatic stress disorder, such as, emotional detachment, difficulty forming close relationships, lack of concentration and somatic symptoms. Ensink, Parry and Chalton (1999, as cited in Cluver & Gardner, 2006) stipulate that it is common for black South Africans to internalize their psychological distress and complain of somatic symptoms, for example bodily pains, stomach-aches and headaches.

From a series of interviews with HIV-positive women in Khayelitsha, it was found that HIV-positive mothers are likely to delay disclosing their status to their children (Soskolne, Stein & Gibson, 2004). Their reason for not disclosing is that their children are too young to comprehend the nature of disease. The mothers also feared the repercussions of HIV/AIDS, such as, stigmatization and discrimination and believed that it would not be in the best interest of the child to be told of their seropositive status. In another South African study conducted in KwaZulu-Natal, it was found that children are often excluded from discussing imminent and recent death of a parent. Such topics are only considered appropriate for adults to discuss, as children are perceived to be too young to understand. Other reasons that were given for children not having been told include: children would get upset; they would not understand; they would not know how to cope and they would not benefit from knowing (Marcus, 1999).

Researchers found that mothers and children might view the consequences of disclosure differently. Mothers often describe their children's externalizing behaviour to have become problematic and report deterioration in the quality of their relationship after they disclosed



their status to them. Their children however, do not recognise any differences across time points. Some of the reasons that mothers and children have such differences in their interpretations or perceptions include: mothers expect their children to experience difficulties post-disclosure, thus, they become over-sensitive to their children's behaviour and mothers who are depressed are likely to exaggerate their perceptions, particularly their perceptions of their children's behaviour. Once children become aware of their mothers condition they often acquire more knowledge of HIV/AIDS, which reduces their anxiety and feelings of uncertainty; this may have offset any potential increases in their report of adjustment difficulties (Shaffer, Jones, Kotchick, Forehand & The Family Health Project Group, 2001).

Several studies conducted in the United States have investigated the effects of parental HIV disease on children and whether a child should be informed about the parent's condition. Forsyth, Damour, Nagel and Andnopoz (1996) investigated children of HIV-infected parents and included a matched comparison group from the same community. Their findings depicted that there were high rates of adverse behavioural and psychological outcomes in both groups; however, children of HIV-infected parents had significantly more internalized symptoms, which became more evident when the parents became ill.

HIV-infected parents tend to disclose their status to older children whom they believe possess a level of emotional maturity and are able to cope better post-disclosure. Children are often not told about their parent's illness even though they witness their parent taking medication on a daily basis. They often question them about it and display concern for their health (Murphy et al., 2001). Younger children are often aware that something is wrong but feel unable to ask, and older children that are informed of their parent's illness are often sworn to secrecy (Nagler, Adnopoz & Forsyth, 1995). Selective disclosure in families, where some children are informed and others are not, illustrates the extent to which secrets are kept in families. Several studies have associated these secrets with unhealthy adjustment (Miller & Murray, 1999; Nagler et al., 1995; Pincus & Dare, 1978).

Shaffer et al. (2001) posit that HIV-infected mothers tend to disclose to their daughters, as they believe that they will take on more family responsibilities when they fall ill. Role reversal or "parentification" (Minuchin, 1974) often occurs when a parent is chronically ill and the children assume the role of the caretaker or parent in the family. "Children whose mothers were HIV-positive reported to more often engage in parental role behaviours, relative to children of HIV-negative mothers" (Tompkins, 2007, p. 113). Children living with HIV/AIDS-infected parents need to take direct care of their parents at times. Their responsibilities include "toileting, bathing, feeding, assisting with transfer and mobility, giving medication and



emotional support" for the infected parent (Bauman & Germann, 2005, p. 101). In addition, they also take on the responsibilities of running the household, taking care of younger siblings and providing an income for their family.

Parentification may become problematic as many children lose out on their childhood because they are required to mature or grow up before their time, thus hindering adequate development. This may trigger feelings of low self-esteem (Barnet & Parker, 1998, as cited in Bauman & Germann, 2005) and social isolation (Smart, 2000) in children. In spite of the negative effects, parentification may also bring out positive qualities in children, such as heightened maturity and coping skills, closer parent-child relationships, feeling needed and valued (Bauman & Germann, 2005), lower levels of depression; elevated social competence and adequate psychological adjustment (Tompkins, 2007).

Working with orphans in South Africa, Bray (2003) found that stigma and secrecy pertaining to AIDS causes orphans to experience social isolation, bullying, shame and feeling unable to fully express their ordeal. Insufficient HIV/AIDS knowledge and education can contribute to children being oblivious to the cause of their parent's death and can make them anxious or fearful that they too will become infected (Marcus, 1999).

Despite the negative psychological impacts, there are suggestions that children's psychological symptoms may improve after a parent's death (Siegel & Karus 1996). This may be because the "anticipatory grief" of a parent being ill, alleviates the stress of later bereavement (Dane, 1994), or it could also be that when the parent dies, the period of uncertainty and distress is replaced by a more stable situation (Siegel & Karus 1996).

2.7. RESILIENCE IN CHILDREN

The adversities of HIV/AIDS epidemic can leave children vulnerable in a multitude of ways. Children of HIV-infected parents or who are orphaned due to HIV are often placed at risk of experiencing negative life events, such as losing one or both parents; being exposed to increased poverty, dropping out of school; being exposed to violence; given the responsibility to head up a household and caring for younger siblings and ill parents as well as being excluded from other social networks and processes (Mallman, 2003; Richter, Foster & Sherr, 2006). In extreme instances, when such vulnerable children become adolescents, they may resort to criminal or deviant behaviour as a means of survival, and could join criminal gangs or experiment with drugs and sex in order to feel a sense of belonging (Motepe, 2005).



Resiliency can be described as the capacity to confront, overcome and become stronger due to the difficulties a person faces in his or her life. It is a universal attribute, which allows individuals or communities to obscure, minimize or overcome the devastating effects of stressors by drawing on the ability to "bounce back" and cope with life's challenges (Grotberg, 2005; The International AIDS Alliance, 2004). In other words, resiliency is the ability to handle adversities that emerge from disease, death, abuse or crime (Mallman, 2003), and can be viewed as the other extreme of vulnerability (The International AIDS Alliance, 2004).

The concept of childhood resilience derives from studies of vulnerable children at risk for negative outcomes, in which protective factors counter risk effects and influence positive adaptation (Masten & Garmezy, 1985). Evidence indicates that environmental risks such as poverty, negative family interaction, parental divorce, job loss, mental illness and drug abuse predispose children to future problems (Masten & Coatsworth, 1998). On the basis of these findings it is expected that children exposed to such negative risks can develop serious psychological difficulties.

However, research indicates that children that have the ability to adapt effectively in the face of adversity (that is to be resilient) are better equipped to survive the damaging effects of stressful life conditions (Masten & Garmezy, 1985).

Lazarus and Folkman's (1984) stress and coping theory defines the ability to cope as an interactional process that includes both the individual's perception of events and management of the outcome. Resilient children have been described as those who understand adverse events, are able to give deeper meaning to such circumstances and believe that they can cope because they have some control over the events (Grotberg, 2003).

Mallman (2003) and the International HIV/AIDS Alliance (2004) highlight the following key points regarding resiliency in children and young adults:

- 1. Children and young people are inherently resilient and have the capacity to cope with very burdensome circumstances.
- 2. Resilient children and young people are able to comprehend these difficult situations because they believe they have some control over what happens to them and in addition, they are able to give deeper meaning to the situation that they find themselves in.



- 3. Resiliency comes from the external resources the child has and from the internal resources, the child has developed, such as a sense of who the child is, and what the child can do.
- 4. Resilience can be strengthened in children by increasing their internal and external resources.
- 5. Family is the primary place where children develop resilience.

Children are born with the capacity to be resilient, however, resiliency has to be encouraged and developed, just like other skills and abilities. Resilience prepares children for the adversity and distress that they may be confronted with as they grow up and in their adult lives (Mallman, 2003). The following factors seemed to offer protection from the damaging effects of stressful life events:

- i. A warm, cohesive and supportive parent-child relationship, combined with firm parental control is associated with increased child competency (Baumrind, 1978; Luther & Zingler, 1991; Smith & Prior, 1995; Werner & Smith, 1982). In addition, Rutter (1996) stipulates that infants that are institutionalised from birth, who did not have a specific caregiver, experience more emotional difficulties than children who form a relationship and attachment with a caregiver. This is due to the fact that they are prevented from forming a bond with one or a few adults.
- ii. The child's personal characteristics, including having a sense of coherence, internal locus of control, competence, problem solving skills and positive self-regard can reduce exposure to risk or lead to experiences that compensate for early stressful events (Garmezy, 1984; Werner & Smith, 1982).
- iii. Social support outside the immediate family, for example, a grandparent, teacher, or close friend who forms a close relationship with a child can enhance resilience in a child as the child learns through positive social interaction and support (Richter et al., 2006; Zimmerman & Arunkumar, 1994).
- iv. A meaningful relationship with at least one caring and supportive adult who actively participates and shows an interest in a child's life, may assist a child in feeling a sense of meaning and connection to that particular person. This may contribute to building a child's resilience (Skinner Cook, Fritz & Mwonya, 2007).

In a study of HIV-infected women and their children, the effects of parental variables on child resilience were explored. The study found that aspect of parent-child relationship; parental monitoring and parental structure in the home were associated with child resiliency, whereas other maternal and structural variables were not (Dutra et al., 2000).



Several longitudinal studies were conducted to determine the relationship of life stressors in childhood to competence and adjustment in adolescence and adulthood. In each of these studies some children were sheltered from negative outcomes, whereas others had lasting problems (Garmezy, 1993; Rutter, 1985, 1987; Werner & Smith, 1992). It was found that a child can become more resilient if they can communicate effectively, solve problems, manage feelings and impulses, build their self confidence, learn survival and social skills, understand how other people are feeling and establish trusting relationships (Mallman, 2003; The International AIDS Alliance, 2004).

Grotberg (2005) recognizes the family, the school and the workplace as three institutions where resilience can be promoted. Families are the basic and primary institutions of most societies; one of the most fundamental places where children learn resilience is at home. "A positive link [has been identified] between promoting resilience and the process of human growth and development" (Grotberg, 2005, p. 2).

In order to attempt to protect children from the multitude of HIV/AIDS risks, an intervention promoting resilience can be beneficial. Such an intervention could act as a guide that teaches children various interpersonal and life skills that may assist them to cope with adverse events in the future. It could also assist mothers to gain insight into personal problems that may complicate or interfere with their relationship with their children. The time spent learning and interacting at such an intervention could facilitate the formation of a closer bond between a mother and a child, thus helping to build the child's resilience. It is important to mention here that the mother-child intervention implemented in this study incorporates various games, activities and practical advice aiming to promote resilience and improve the adaptive functioning of the participating children (6 to 10 years) of HIV-infected mothers.

2.8. CONCLUSION

Thirty-three million people worldwide are living with HIV. Sixty per cent of global women infected with HIV and 90% of all children living with HIV reside in sub-Saharan Africa. About 12 million children who have lost one or both parents due to the disease are from the same region (UNAIDS, 2008). The AIDS epidemic is a catastrophic problem, particularly in sub-Saharan Africa. South Africa is now faced with the daunting challenge of protecting the vast number of vulnerable children, and providing them with adequate resources in order for them to become productive members of society.



By understanding the psychosocial impacts of HIV/AIDS on mothers as well as the gender inequalities imposed on them by society, we are able to empower women further so that they are better equipped to cope with their situations. In addition, they are able to deal more effectively with their personal experiences which ultimately impacts on their relationships with their children. Promoting more effective interaction between mother and child helps build resilience in children, enabling them to cope with the challenges of HIV and other life events. Children's health and well-being is inextricably linked to their mother's physical, emotional and social health, social circumstances and child-rearing practises (Schor, 2003).

The literature highlighted in this chapter has contributed to the understanding of the HIV-infected mother's experiences and has shed light on how she perceives HIV and its effect on her family relationships, particularly on her relationship with her children. In addition, a clearer understanding of the purpose and benefits of a mother-child intervention, aiming at empowering mothers and promoting resiliency in children, is established.

The following chapter presents a detailed description of the theoretical framework used in this study.



CHAPTER 3 THEORETICAL FRAMEWORK

3.1. INTRODUCTION

The research was carried out using a systemic theoretical paradigm, specifically the family systems viewpoints set out by Selvini-Palazzoli, Boscolo, Cecchin and Prata (1978), who are known as the Milan family therapy team. This chapter commences with a broad description of the differences between the linear and circular perspectives. In order to clarify the presented literature and the research position of this study, the relevant terminology will also be explained. A distinction between first-order and second-order explanations will be explored as part of the systemic approach used in this study. More specifically, the key principles of the Milan approach will be highlighted, as this approach attempts to apprehend the relationships between family members as well as the interactive patterns of families.

3.2. LINEARITY VERSUS CIRCULARITY

To understand the assumptions made in systems theory, it is important to define, and distinguish between, the linear and circular approaches, especially with regard to the principles of each approach and how they depict the notions of problems and causality.

The traditional paradigms, such as the psychodynamic and cognitive behavioural approach, are considered to be linear models, and are generally characterised by reductionism and their cause-and-effect perspectives - A causes B and thus leads to C. These perspectives focus on the past as a means of remedying the causal factor creating the problem, and view the individual in isolation as being separate from his or her context. These perspectives consist of subjects and objects that can be studied objectively. Linear perspectives try to explain why certain aspects occur by looking at the cause of the problem. It is assumed that the cause of the problem can be fixed (Becvar & Becvar, 2002; Bateson, 1979; Jackson, 1967; Keeney, 1983; Watzlawick, Beavin & Jackson, 1967).

In contrast to linear models, circular models - for example, systems and ecosystems theory - direct our attention away from the individual and towards relationships between individuals and the context of their behaviour. Reciprocal causality replaces the cause-and-effect approach (Watzlawick et al., 1967) and asserts that subjectivity is inevitable. The observer



creates his/her reality. The approach is holistic and takes the context into account. The mutual influence of the parts of the system creates patterns of interaction, in other words, they all give feedback to the system – C leads back to both A and B – thereby affecting the entire event. Great emphasis is placed on what is happening *here and now*; thus the question "What?" can be answered by looking at the dynamics.

Traditional theories are seen as mechanistic in nature, while circular theories are viewed as being cybernetic. In addition, research within the linear approaches employs an objective methodology, and the results are used to *prove* certain aspects true and apply results mechanically. Circular approaches, on the other hand, use a consensual methodology and research findings are used as guidelines which are applied creatively (Bateson, 1979, Becvar & Becvar, 2002; Jackson, 1967; Keeney, 1983; Watzlawick et al., 1967).

3.3. DEFINING RELEVANT TERMINOLOGY

The following terminology is relevant for a better understanding of the theoretical framework used in the interpretation of the data.

3.3.1. Family subsystems

This term refers to the components of a family's structure which exist to carry out various family tasks. Minuchin (1974) highlights three subsystems, namely: the spousal subsystem, the parental subsystem and the sibling subsystem.

3.3.2. Family structure

For Minuchin (1974), the term "family structure" refers to enduring patterns of interaction which serve to organise the subsystems of the family into consistent relationships. The structure consists of rules and patterns of interaction between and within subsystems, which govern the family by defining the rules, roles and patterns that will be acceptable within that specific family. Hence, the structure organises the way the family interacts. Therefore, the relationships within and between subsystems define the structure of the family.

Even though all families have a unique, idiosyncratic structure, they all share certain generic structural elements. Firstly, they all have some form of hierarchical structure in which the parents have greater authority than the children. Secondly, reciprocal and complementary



functions are imposed on family members by the roles and functions that they serve in the family.

3.3.3. Relationship styles

Relationships are assessed and labelled according to their characteristic patterns of interaction. Bateson (1979) identifies two relationship styles;

- A Symmetrical relationship is based on a relationship of equality, for example, both parties are dominant, or both are submissive. In other words, both parties exchange similar kinds of behaviour. Such relationships, however, run the risk of becoming competitive.
- A Complementary relationship is based on a relationship of inequality or differences, for example, one party is dominant and the other is submissive. In other words, both parties exchange opposite kinds of behaviour. This type of relationship has the potential for rigidity, for example the more dominant she is, the more submissive he becomes and the more dominant she becomes, and so on.

Keeney (1983) states that if these two styles were mixed a balance could be achieved as the roles and behaviours become flexible. This would be the case in healthy relationships. Becvar and Becvar (2002) refer to this description as a *parallel relationship*.

3.3.4. Family rules

These are implicit, unwritten rules or norms for behaviour according to which the system operates. These rules determine what type of behaviour is expected or prohibited in this family. The rules define relationship patterns of that particular, unique family system. Over time, these rules and roles develop into recurring patterns of interactive sequences among the members, which are predictable, familiar and stable. These patterns of interaction become the way in which the family rules and roles are transmitted and also reinforce the relationships between family members. More specifically, these rules express the values of the system and determine the closeness, hierarchies, area of specialisation and expertise, and patterns of co-operation between the members of the family system (Gurman & Kniskern, 1991; Minuchin, 1974).



3.3.5. Boundaries

Rules form the basis of the system's boundaries. Boundaries determine the flow of information in and out of the system, and between sub-systems of that system by determining what information is allowed to enter or leave the system and who may participate in the subsystem's interaction and how such participation is to take place. In addition, boundaries within the family vary according to their degree of permeability, which determines the nature and frequency of contact among family members (Minuchin, 1974). The degree, to which these boundaries allow information to be let into the system from outside, will characterise that system as being either *open* or *closed*. A healthy family is characterised by *negentropy*, which means that there is an appropriate balance between openness and closedness, resulting in a tendency toward maximum *order* in that system. An unhealthy family is characterised by *entropy*, which means that it is too open or too closed, resulting in a tendency toward maximum disorder or disintegration (Becvar & Becvar, 2002).

Minuchin (1974) states that boundaries need to be well-defined to allow members to carry out their tasks without unnecessary interference, while at the same time being open enough to permit contact between members of the subsystem and other systems. The rigidity of the boundaries between subsystems will determine where these boundaries are located on a continuum between enmeshed and disengaged.

Minuchin (1974) identifies three types of boundaries between subsystems:

- Clear Boundaries are firm but also flexible, encouraging supportive behaviour as well as autonomy for the family members, so that they individuate while maintaining their sense of belonging. This is the ideal type of boundary as it allows for easy access across subsystems in order to successfully facilitate adaptation to any developmental challenges that occur.
- Rigid Boundaries in a system isolate the members from each other so that they are disengaged from one another. In such situations, there is little support and interdependence for the members and the family may also be isolated from the external world. In such a disengaged system, in which every member is involved in their own issues, there is restricted access between subsystems and so it is very difficult for one member to mobilise support from others. Such boundaries facilitate too much independence or autonomy and a lack of support or nurturance.



• Diffuse Boundaries refers to the lack of distinctions between subsystems, whereby there is too much access between subsystems. Here, the parents are too involved with the children, as well as being very intrusive and over-protective, and do not adapt easily to the children's developmental need for more autonomy. Parents will continue to restrict individualisation and optimal development. As adults, the children may experience difficulty in interpersonal relationships as they will remain attached to their family-of-origin. Such systems are referred to as "enmeshed" – there is too much support or nurturance and not enough independence or autonomy.

3.3.6. Power, alignments and coalitions

Minuchin (1974) makes use of these three terms to indicate the positioning of family members. "Power" refers to the influences that a member has on an activity's outcome, including who the decision-maker is, and who carries out the decisions that are made. Minuchin uses the term "alignment" to indicate the manner in which family members join with one another or oppose one another, when carrying out a family activity. More specifically, the term refers to the emotional or psychological connections that the family members make with one another. Some types of alignments are formed in order to increase the power of a subsystem or of certain members in the family. These alignments may create dysfunction in the family, particularly if they oppose other members, in which case, the alliance would be referred to as a "coalition" or "triangulation" between two members against a third (Haley, 1976; Minuchin, 1974; Selvini-Palazzoli, Boscolo, Cecchin, & Prata, 1978).

3.3.7. Feedback

It is through feedback loops that the parts in a system are interrelated and maintain the systems functioning. The overt and covert rules which govern the system maintain the feedback in families. Feedback occurs when information is fed back into the system, and influences the system's later response (Bateson, 1979; Bradshaw, 1988; Keeney, 1983). Feedback can be either negative or positive.

Negative Feedback is "deviation - countering feedback" (Bateson, 1972, p. 429). This feedback opposes the direction of the initial change that produced the feedback. In other words, when information about past behaviour and stability is fed back into the system to decrease the original behaviour, no change occurs in that system. Homeostasis is thus achieved and the status quo of the system is maintained (Bateson, 1972; Becvar & Becvar, 2002; Watzlawick et al., 1967).



Positive Feedback is "deviation-amplifying feedback" (Bateson, 1972, p. 429). This type of feedback amplifies the direction of the initial change that produced the feedback. In other words, the result of previous behaviour is fed back into the system to increase the original behaviour, resulting in a change in that system. The behaviour is either increased or decreased, in order to maintain the stability of the system (Bateson, 1972; Becvar & Becvar, 2002; Watzlawick et al., 1967).

3.3.8. Feedback and homeostasis

Homeostasis means that the family system seeks to maintain its customary organization and functioning over time; it also tends to be resistant to change (Jackson, 1967). It is through negative feedback that a family system maintains its homeostasis, thus reducing any deviation that may result from the introduction of new information. A system has limits and tries to restrict behaviour to a narrow range, in other words, it tries to keep all interactions within the range set by those limits. If the system senses that the threshold is being approached (meaning that the behaviours are about to exceed its parameters), it will be knocked off balance. Thus, certain mechanisms will have to be activated in order to restore the equilibrium or balance within that system. The mechanisms that maintain homeostasis operate according to certain rules that set the range within a given behaviour which could vary. In closed system families, the feedback loops are mostly negative and work to keep the system frozen and unchanged (Becvar & Becvar, 2002; Bradshaw, 1988; Gurman & Kniskern, 1991).

3.3.9. Feedback and change

There are times when the system has to change to meet outside demands, for example; the birth of a new child; a loss of a member; the maturation of a child; an adolescent leaving home, etc., and it does this through *positive feedback loops*, which have the potential to reset the parameters of the system, allowing for more varied interactions. Here, the consequences of the system's output are fed back into that system and this causes the output to increase. Positive feedback challenges destructive and unexamined rules (overt & covert) and can also break up the frozen status quo of a system (Becvar & Becvar, 2002; Bradshaw, 1988; Gurman & Kniskern, 1991).



3.3.10. Circular patterns of interaction

As mentioned earlier, circular perspectives posit that behaviour and beliefs do not occur in isolation. Thus, the interrelational context in which individuals are based needs to be taken into consideration, focusing on the evolving relationships of the family members within their environmental, historical, developmental and ideological contexts. From a circular standpoint, cyclical sequences of interactions which interconnect with family beliefs are depicted. However, these patterns of relating and believing could recursively serve to perpetuate dysfunctional behaviours and cognitions (Boscolo & Bertrando, 1996; Selvini-Palazzoli et al., 1978; 1980). In other words, a system that has overly-rigid parameters (boundaries) and is easily threatened by change, will be extremely reliant on negative feedback to maintain that system within its parameters, preventing it from making the necessary adaptations (Keeney, 1983).

Since all behaviours are communications, meaning that they have feedback effect and they provide information, the "symptom" (problematic behaviour) in a dysfunctional family is also communication that has feedback effect. Therefore, to understand the symptom of an individual from a systemic perspective it needs to be viewed in the context of the whole system, focusing on the effects of the symptom on others in the system, and its effect on the whole system itself which focuses on the effect of that effect. As such, the symptom has a function to play in maintaining the stability of the family and it, in turn, is also maintained by the system. In other words, the system and the symptom are recursively related: the system maintains the symptom since the symptom is one link in a circular chain of interactions and the symptom maintains the system by performing a negative feedback function for that system (Keeney, 1983; Selvini-Palazzoli et al., 1980; 1978).

3.4. DIFFERENTIATING BETWEEN FIRST-ORDER AND SECOND-ORDER CYBERNETICS

3.4.1. First-order cybernetics

First-order cybernetics, or simple cybernetics perspective, compares a system to be like a "black box" that receives and delivers inputs and outputs (Waltzlawick et al., 1967). These inputs and outputs are perceived by the observer in order to understand the patterns of the system and to formulate an understanding of what is going on in the system. Thus the focus of the first-order therapist is to describe, or punctuate (Batson, 1979), what is happening to



the system from the perspective of an outsider as he/she does not regard him/herself as part of the system (Becvar, 2000; Keeney, 1983).

Reality is viewed as operating according to the principles of recursiveness (reciprocal causality) and feedback (self-correction). Working from a systems perspective, therapists need to understand any event or problem by viewing it in context to the mutual interaction and influence of those involved. This implies that a problem exists in relation to a context where meanings are derived; each part influences every other part and there are no individual isolated units. Thus, from this perspective therapists are less concerned with revealing the cause of a problem, but rather look for the reciprocal causality that emerges from relational interactions. First-order therapists aim to understand the relationship patterns that maintain the problem within that system and how systems organise themselves around these problems (Bateson, 1979; Becvar & Becvar, 2002; Efran & Lukens, 1985; Hoffman, 1985; Keeney, 1983; Watzlawick et al., 1967).

As human beings, we are constantly interacting with others, thus we jointly influence one another and generate information which is fed back into the relationship or system. As described earlier, feedback can either be negative or positive and is a process of recursion involving self-correction, i.e. information regarding previous behaviour is fed back into the system, in a circular manner, in order for the system to either change or remain the same so that it can survive. The context of the feedback process dictates whether the system will view the feedback as good or bad (Becvar & Becvar, 2002; Keeney 1983; Watzlawick et al., 1967).

Therefore, at a content and processing level, therapists do not modify systems or treat families. Rather, they alter behaviour and gauge the impact of the new behaviour by assessing reactions to it. They then react to the reactions in an ongoing modification process. This process is seen as a strategy in which a context is to create a desired outcome - a change in behaviour that can be viewed as a logical response (Batson, 1979; Keeney, 1983). However, the amount of information that a system will permit depends on its rules and on the permeability of its boundaries, i.e. how open or closed a system is. The principle of openness and closedness indicates the degree to which a system screens out or allows new information into the system (Keeney, 1983; Minuchin, 1974).

A system is known to have habitual interaction patterns or redundant patterns ("equifinality") of behaviour and communication that tends to be repeated. It is often these redundant behavioural patterns that keep the system immobilised or stuck, since the processes in

operation are no longer successful. In other words, regardless of what the content is, the process will generally be the same, irrespective of the topic or the manner in which the members decide to tackle the problem. In contrast, "equipotentiality" refers to the different end states that can be obtained from the same initial conditions, implying that it is not possible to predict outcomes, such as those of interventions (Becvar & Becvar, 2002; Keeney, 1983). This fits in with the focus on the *here and now* (the process) rather than trying to figure out *why* something has happened, which is one of the major differences between traditional and cybernetic perspectives (Becvar & Becvar, 2002). Therefore, a system which is "stuck" may need new relevant information (feedback) that offers an understanding of the context and patterns of behaviour and communication which maintain the problem (Becvar & Becvar, 2002; Keeney, 1983).

According to Keeney (1983) feedback regulates and confirms communication underlying experience and interaction. Three basic principles underlying communication and information processing, which derive from communications theory and have had a significant influence on family therapy and simple cybernetics, have been outlined by Keeney (1983) as follows:

- It is impossible not to behave.
- We cannot not communicate.
- The meaning of behaviour, and not the "true" meaning of the behaviour, is true for the person giving it a specific meaning. Reality is subjective and a function of one's frame of reference.

Additionally, three modes of communication can be identified, namely: verbal communication, (the spoken word); non-verbal communication, and context. Verbal communication relies heavily on the content of what is being said, while non-verbal communication relies on body language and voice tone which modify the verbal aspect in order to interpret what is meant. The context in which verbal and nonverbal communication take place determines the rules of the interaction. Context is seen as the most powerful aspect of communication, since it influences how people relate in the process. If we communicate congruently, the content (what is said) and process (how it is said) will match, lending clarity to our interactions. Incongruent communication may cause confusion and could result in many interrelational problems (Bateson, 1972; Watzlawick et al., 1967). These modes of communication take place on different logical levels. "Metacommunication", is communication about communication and it takes place on a higher logical level (Bateson, 1972). When we talk about the way we are communicating, we may avoid miscommunication (Boscolo & Bertrando, 1996).



The foremost rule underpinning systems theory is that the whole is greater than the sum of its parts. Therefore, two individuals plus their interaction, equals three. When a system encompasses more than two individuals, it signifies that there is the potential for a greater number of relationships (Becvar & Becvar, 2002). This principle of relationship implies that if there is change in one part of the system, the whole system is affected (Bateson, 1979; Efran & Lukens, 1985; Keeney, 1983).

From a systemic perspective it would be incorrect to say that there is a goal or purpose as these notions are viewed as linear, suggesting causal thinking (Pask, 1969, as cited in Becvar & Becvar, 2002). However, in keeping with simple cybernetics, the observer of a system could imply the purpose or goal of a system according to his or her subjective reality (Dell, 1982, as cited in Becvar & Becvar, 2002; Keeney, 1983; Maturana, 1978). Hence, the concepts "equifinality" and "pattern" imply that the system becomes its own best explanation. On the level of first-order change (which is not the same as first-order cybernetics), change is a difference that takes place in a system consistent with its rules, which in itself remains unchanged. Put more simply, the content of the behaviour changes, whilst the system continues as it always has. Such change is often superficial and transitory. In second-order change the system itself changes as the rules of the system are changed. This type of change is more effective and long lasting as the interactional cycle, including the solution that maintains the problem is broken (Becvar & Becvar, 2002).

The following example is relevant to the study, and it is intended to clarify the distinction between these two types of change. When a child is disobedient, his mother may try to discipline him in a number of ways. She may shout at him, and when this does not work, she might punish him. If this does not work, she might try speaking to him; if this fails, she may try, unsuccessfully, to discipline the child by beating him. In all of these attempts none of the solutions for the perceived problem (i.e. the child's behaviour) work. In effect, each of these attempted "solutions" only serves to exacerbate the child's behaviour. Thus, a vicious circle or a positive feedback cycle is created between the attempted solution and the bad These changes are referred to as "first-order changes" and they are not behaviour. considered to be real changes; they are merely different items or solutions grouped together in the same category. This "category" could be entitled: "Trying to stop the child from behaving badly". In second-order change, the mother has to stop her attempted solutions. More to the point, she has to stop trying to solve the problem using solutions that fall under the category of: "Trying to prevent the child from behaving badly". This means that the mother needs to try something that is the complete opposite of her previous solutions. Her new solution should feature in the category: "The child's behaviour is actually a good thing



for you/ him, so you should stop trying to restrict this behaviour. Instead, you should encourage this 'bad' behaviour'. By changing or reframing the behaviour, the feedback cycle, which maintains the problem behaviour, is broken and the category of initial attempted solutions is altered.

From the moment the observer is included as part of the system and the context, the concept of second-order cybernetics comes into effect. This is explained in more detail in the next section.

3.4.2. Second-order cybernetics

Second-order cybernetics, or *cybernetics of cybernetics*, differs from first-order cybernetics in that it reflects relational processes that cannot exclude the observer from the system that he or she is observing (Boscolo, Cecchin, Hoffman & Penn, 1987). The understanding is that the observer uses his or her personal frame of reference (subjective reality) to interpret the observed system's interaction. From this perspective, the observer becomes part of the observed; the system includes the observer and the "black box" (Maturana & Varela, 1980). It is also a way of viewing the wholeness of a system, i.e., the system is seen as a whole entity rather than as a composite entity made up of parts. This level of describing a system is the system's highest order of recursion which Maturana and Varela (1980) refer to as *autonomy*. In other words, there can be no outside independent observer of a system, since anyone attempting to observe and change a system is by definition a participant, who both influences and interprets that which they study and is in turn influenced by that system (Anderson, 1997).

This view is in sharp contrast to the first-order cybernetic perspective which distinguishes between two separate systems: the therapist system and the problem-client-family system. Whereby the therapist remains an external observer and expert who attempts to bring about change by implementing interventions from the outside (Anderson & Goolishian, 1988; Boscolo et al. 1987; Hoffman, 1991). Vorster (2003) criticises the notion of second-order cybernetics, which holds that therapists do not have expert knowledge. He feels that this view is demeaning and that it reduces the therapist to an immobilised non-expert. Vorster is of the opinion that the focus should be on interactions between systems (i.e. a higher logical level than the system itself), and that change can be deliberately made to the interaction within the system (referring to second-order change, which will be discussed later). He states further that with adequate training, an observer can be more accurate in his/her



perceptions and can set certain deliberately selected objectives for therapy than someone who lacks such training.

Cybernetics of cybernetics considers reality to be self-referential, implying that there is no absolute truth and that reality exists merely as "multiverse" of individual constructions and perceptions. We live in a multiverse of many equally valid observer-dependant realities; as Maturana (1978, p. 61) states, "we literally create the world in which we live by living in it". The focus of therapy is thus on meanings rather than on behaviour.

Given that the observer is part of the system, there cannot be any reference made to the outside environment. Cybernetics of cybernetics perceives the system to be closed with unbroken boundaries, utilising only internal feedback, since the emphasis can only be on the internal structure. The internal structure is recursive and the emphasis in on the mutual connectedness of the observed and the observer and not on the analysis of the inputs and outputs, as in the case of simple cybernetics (Becvar & Becvar, 2002; Maturana & Varela, 1980).

Since the feedback loops are closed and no input or output is experienced from the outside world, the system feeds upon itself (Bateson, 1972; Maturana, 1978). Second order cybernetics suggests that there are two types of cybernetic feedback:

- Negative feedback (morphostasis, introduced by first-order cybernetics) which "describes the system's tendency towards stability".
- Positive feedback (morphogenesis, introduced by second-order cybernetics) which "refers to the system-enhancing behaviour that allows for growth, creativity, innovation and change, all of which are characteristics of functional systems" (Becvar & Becvar, 2002, p. 69).

In a healthy family system, there is a balance between the two types of possible change, which means that the system is stable, but it is also flexible enough to change when necessary. Keeney (1983) stipulates that change and stability are different sides of the same coin and systems need both. This implies that the members can only change if they have a "roof of stability" over their heads, and they can only be stable via processes of change i.e. the parts of the system have to change in order to maintain their stability. An unhealthy family, on the other hand, lies at one of the two extremes: it is either too chaotic, with no stability, or it is too rigidly stuck in one way of being. Moreover, a pathological family is stuck in a rigid, dysfunctional homeostatic phase (negative feedback), and so it will respond to the demands for change by increasing the rigidity of its interactional patterns.



Systems are also structurally determined, meaning that a system determines the range of structural transformations without losing its identity and how it operates, i.e. its operation is a function of how it is structured. Consequently, the system's structure limits it in terms of what it can or cannot do, as well as what its structure allows it to perceive and nothing else. Second-order cybernetics views the external environment only as a trigger or perturbing agent that provides the system with a context for an occurrence, allowing the system to respond in a manner that is determined entirely by its own structure (Becvar & Becvar, 2002; Boscolo, et al., 1987; Keeney, 1983; Maturana, 1978; Maturana & Varela, 1980).

Moreover, living systems, like humans, are structurally plastic systems, which means, that they can change their structures when they interact with other structurally plastic structures. The extent to which systems are able to mutually co-exist and interact with each other in a given context is referred to as structural coupling in a consensual domain. Here, the systems co-ordinate their actions with each other, generating a linguistic domain. In this domain, we agree on certain meanings consensually, and things become what we agree to call them in the context of a common language system (Becvar & Becvar, 2002; Keeney, 1983; Maturana, 1978; Maturana & Varela, 1980). It can therefore be assumed that if systems are able to adjust structurally then structural coupling can occur. Change is therefore a process of structural transformation in the context of organisational consistency (Becvar & Becvar, 2002; Keeney, 1983; Maturana, 1978; Maturana & Varela, 1980).

Systems exist in a non-deterministic context and seeing that there is only reciprocal causality "the life of a system is a process of non-purposeful drift within a medium" (Becvar & Becvar, 2002, p. 83). We do not move towards a specific truth or progress, but we move towards new ways to coordinate our actions with others in order to survive (Becvar & Becvar, 2002; Maturana, 1978).

From this perspective, the therapeutic intervention is viewed as a perturbation of a system by a therapist who merely co-exists in the therapeutic domain, focusing on the underlying patterns of feedback processes. A therapist, therefore, nudges or perturbs a system by instigating second-order change in the process (Becvar & Becvar, 2002; Keeney, 1983; Maturana, 1978). Second-order change should not be confused with second-order cybernetics; second-order change refers to a change in the rules of a system as opposed to first-order change which is change that occurs in some aspects of the system, but according to the existing rules of that system (Becvar & Becvar, 2002). Second-order change is meaningful, since it implies a profound change, and an altered way of thinking (Becvar & Becvar, 2002; Vorster, 2003). Thus, from this stance, the here and now is important in



healing. Healing can be achieved by reflecting on the existing interactional patterns that maintain the system's status quo and facilitating change in these relational patterns (Becvar & Becvar, 2002).

It is imperative, however, to remember that reality exists merely as multiverse of individual constructions and perceptions and that there are many equally valid observer-dependant realities. Cybernetics of cybernetics recognises that different members of a system have different views, each of which are valid, even though these different views (or "punctuations") belong to the same system (Bateson, 1979; Maturana, 1978). Thus, in order to understand the client, the therapist must understand how s/he punctuates his/her own reality. The therapist must also be aware of his/her own personal views, issues or prejudices as these may hinder the therapeutic process by creating misunderstanding (Cecchin et al., 1994; Hoffman, 1988; 1991).

Cecchin Lane and Ray (1994) define prejudices as: "a preconceived preference or idea. A bias. To elaborate on this brief definition...the notion of prejudice is not in and of itself a negative thing" (p. 7). It is further stated that when therapists are aware of what their prejudices are, these may become useful in therapy and the understanding of the presenting problem. Prejudices constitute any pre-existing thoughts that may contribute to one's view, perspectives of, and actions in a therapeutic encounter. From a circular perspective however, there is interplay between the therapist's prejudices and those of the client, since they reciprocally influence one another in the system.

In addition, it is important to remember that in order to understand a system we cannot divide it into parts nor can we isolate individuals from their environment. Individuals need to be viewed in context so that the relationships that exist between them, as parts of a system, benefit our understanding of differences. According to Keeney (1983), we are not surrounded by a world of opposition; rather, we exist in a realm of both/and dichotomies. A therapist working from this theoretical stance needs to consider both/and dichotomies and the contextual utility of each side of the coin (Becvar & Becvar, 2002). It is in the process of contrasting, that difference can be noticed and the meanings of both sides understood. Therefore, conclusions that we make about what is considered to be good or bad, right or wrong is only relative within its context (Becvar & Becvar, 2002, Cecchin, et al., 1994; Keeney, 1983; Maturana, 1978). Thus, in this study, it is important to view the mother-child interaction within the family system, and to compare it to other mother-child subsystems and families in the study, in order to obtain an understanding of how HIV and the intervention impact on family interaction. It is also vital to understand these mothers define and perceive



problems within their system and not to assume that a problem is universal across all families. For example, HIV may be seen as a major problem in one family; in another it could be views as a blood disease that merely requires careful monitoring.

Hoffman (1985) asserts that second-order cybernetics is not a method of therapy, but rather a stance that does not specify a particular working method. Second-order cybernetics creates a set of guidelines which help us put the method we use into practice. Hoffman highlights the following second-order characteristics (p 393):

- 1. An "observing system" stance and inclusion of the therapist's own context.
- 2. A collaborative rather than a hierarchical structure.
- 3. Goals that emphasize setting a context for change, not specifying a change.
- 4. Ways to guard against too much instrumentality.
- 5. A "circular" assessment of the problem.
- 6. A non-pejorative, non-judgemental view.

Becvar and Becvar (2002) propose that an understanding of both first and second-order cybernetics may be a valuable tool in recognising and understanding the processes of human interaction. The one cannot exist without, nor be replaced by the other.

3.5. A SYSTEMIC DESCRIPTION OF INTERVENTIONS

In this research the various systems and how they are structured will be evaluated from a systemic perspective by focusing on the system's characteristics and which patterns are involved in that specific system. It is imperative to remember that a system is a network made up of parts that are in a state of mutual interaction or recursively related; in which every part affects and is affected by all other parts (Bateson, 1979; Efran & Lukens, 1985; Keeney, 1983). Moreover, a living system, such as a family, exchanges information with its environment. It is a self-correcting network that processes information and governs itself through rules (Bateson, 1972; Maturana, 1978; Minuchin, 1974). Families are, therefore, best understood in context; it must be noted that the presenting problem serves a function within the family, and that the scrutiny of "stuck" families requires an analysis of boundaries, coalitions, power, triangles and circular cycles (Becvar & Becvar, 2002; Maturana, 1978; Minuchin, 1974; Vorster, 2003).

From a systemic perspective it is believed that there are multiple truths about the family, called "objective descriptions" (Maturana, 1978). These are merely social constructions that



reveal more about the "describer" than about the family. The family's reality is nothing more than an agreed upon consensus that occurs through the social interaction of its members (Gergan, 1985). For example, the ways in which the family members have each defined their own roles and identified the problem within the home, have been mutually agreed upon through their patterns of interaction.

It can thus be said that there is no correct manner in which the participants and the therapist/observer are expected to behave; instead all statements about the truth are validated through the criterion of social consensus. Consequently, it is more appropriate to be conversing about the participation in the construction of consensuality as opposed to reality-testing. Since there is no accurate behaviour for the family members, there can also be no accurate outcome for the research process – thus the purpose of the intervention is to actively contribute to the co-constructing of consensuality and to changes in co-ontogenic structural drift (Cecchin et al., 1994; Keeney, 1983; Maturana & Varela, 1987; Tomm, 1984a). From this approach the participant is viewed as being as much of an expert as the therapist is (Cecchin et al., 1994; Hoffman, 1990; Tomm, 1984b). The therapist takes on the dual role of observer of the effects of specific actions and of a participant-actor. It is this dual role that makes change a possibility (Maturana & Varela, 1980). Thus the therapist can only co-create a new reality together with the participant (Maturana & Varela, 1987).

Furthermore, the researcher cannot claim to have an objective view or metaposition (Haley, 1976) of what the participant is experiencing intrapersonally or interpersonally within the structure and boundaries of their family. All that the researcher "knows" is his or her constructions of how the family constructs its own realities (Maturana, 1978). This could be evaluated through circular questioning (Fleuridas, Nelson & Rosenthal, 1986; Hoffman, 1985; Penn, 1982; Selvini-Palazzoli et al., 1980) so that a broader understanding can be obtained.

Working from this perspective, the researcher should also be aware that each participant has his or her own view of reality and description of the family – the family encompasses multiple perspectives or multiple realities; in addition the researcher will have a part in constructing the reality being observed (Hoffman, 1989; Keeney, 1982). However, each family's interpretation of reality is limited by the constructions that the members make about themselves as individuals or as a family; these constructions give meaning to the family's experiences and are self-perpetuating (Keeney, 1982; Maturana, 1978). Thus, from the description given earlier about how the family constructs its own reality, it can be said that this would be the consensus description as each member also has their own additional views of the family.



Symptoms or problems, from a systemic approach, have no objective existence independent of the observers (those who complain about it). In other words something is not a problem until somebody defines it as such through language (Becvar & Becvar, 2002; Boscolo et al., 1987; Efran & Lukens, 1985; Maturana & Varela, 1980). It is important to note that this does not mean that problems do not exist, because they do exist but only in the domain of meanings or language; problems are ascriptions of meanings arising from within a particular context. A problem only exists within a frame of reference that defines or labels it as such (Keeney, 1983). From this perspective, we can thus say that the family have consensually agreed that there is a problem within their home; however, they may be unsure of what the exact problem is, as they may all have their own view of what can be defined as a problem (Becvar & Becvar, 2002). It is also typical of family members to see a problem in a linear, cause-and-effect fashion. Shifting the blame on to others may be easier as they either do not want to take responsibility for the role that they play in creating the problem, or they may not be aware that they play a role in it (Becvar & Becvar, 2002). This means that outsiders may see HIV as a problem in families; however, families may not share the same views unless they themselves see HIV as being a problem. This study focuses on how the family members interpret the role of HIV in their own families.

Since systems are structure-determined and can do only what their structure determines it to do, systemically any symptom or behaviour is described to be logical in that particular context, which includes the structures of all those who are "languaging" about it as a problem (Anderson & Goolishian, 1998; Maturana & Varela, 1987, Varela, 1989).

Moreover, interventions are not perceived as a process of using standardised techniques, as if they were "magic pills" or "quick-fix recipes", which are supposedly powerful, with inevitable outcomes (Keeney & Sprenkle, 1982). Instead, given the notion of structure-determinism, it is believed that no one can impose or inflict their views on others; there are only perturbations of structure with subsequent compensation which is unpredictable. This means that the technique that is implemented does not specify how the system will respond; rather it is the system itself that determine how it will react to a perturbation. Thus, the researcher needs to acknowledge the existing structure of the system with the realisation that the system is doing the best it can within the confines of that structure (Becvar & Becvar, 2002; Boscolo et al., 1987; Keeney, 1983; Maturana, 1978; Maturana & Varela, 1980).

Ultimately, the therapist would need to interact with the family during the intervention, in such a way as to perturb that system and to co-construct different realities or different perspectives. Systems can change or alter their structures by interacting with other systems



through the process of structural coupling in a consensual domain (Maturana & Varela, 1987). Therefore, the reciprocal interaction between the family system and the therapist would be based on both parties' perceptions of what is going on within the system. These perceptions would be influenced by both parties' personal experiences, and thus both systems would be influencing each other (Anderson, 1997; Hoffman, 1988; Keeney 1982). For example, if the participant is expressing her disbelief at contracting HIV, the therapist may ask questions so that she can understand what the participant understands by the term "disbelief". During this process the researcher may also use examples to clarify her understanding which may influence the participant to alter or incorporate the researcher's perspective.

It is also important to remember that techniques are simply tactics used to perturb a system (Keeney, 1983; Maturana, 1978). The therapist cannot view his or herself as a change-agent who operates on others so that he or she can transform them. Instead, the therapist must get into an unavoidable co-ontogenic structural drift with the participant/s, with the goal of perturbing the system in such a way that it will compensate with more functional behaviours for that system. The system, however, the system will only react according to its own structure (Varela, 1989). During this process a context is created to facilitate change whereby the system engages in self-correction (Keeney, 1983). Structural changes which occur as a result of this drift will also occur for the therapist as he/she becomes part of the system (Efran & Lukens, 1985; Hoffman, 1988).

Perturbation is achieved by introducing "meaningful noise" (Varela, 1981) into that system, this means that, in order for a system to alter its behaviour, it must have new information to draw on so that the members can modify their perceptions and become "unstuck" from their rigid frames of reference, concerning their actions. In order for the participants to accept and find meaning in this new information, it is vital that it be meaningful to the participants' worldview, metaphors or language and it should also be presented to the participants in a manner that acknowledges both stability and change (Becvar & Becvar, 2002; Keeney, 1983; Varela, 1981).

The effects of interventions are always "stochastic" (Bateson, 1979; 1972), meaning that change occurs in a partially random manner. Accordingly, when the context is altered or changed the behaviour would also change, thus defining the new behaviour as a logical response; however, the exact nature of these responses cannot be determined. Even though there are only a few possible changes that can occur, due to the system's determined structure, it is not possible to predict which of these behaviours will be selected.



Consequently, the researcher can only disrupt the patterns or perturb the ecology through use of an intervention; the system will do the rest as it is self-corrective and self-maintaining. The purpose of the intervention is purely to provide a context to facilitate this self-correction. This is done by offering the system new information in order to assist it in maintaining its stability as it changes its structure and maintains its organisation (Becvar & Becvar, 2002; Keeney, 1983; Maturana & Varela, 1980; Maturana, 1978).

It is also crucial to remember that, in contrast to the traditional and first-order cybernetic perspectives, second-order cybernetics views the therapist and the researcher as observers with no privileged access to reality, and thus, they lose their "expert position". In addition, the therapist and the researcher need to be consciously aware of their own personal prejudices and constructions of reality in order to examine how these may influence the "expert-client" interaction, and consequently the outcome of the intervention and research process (Cecchin et al., 1994; Hoffman, 1988; 1991). Hoffman (1991) states that the inclusion of a therapist into a system generates a need for the therapist to self-reflect on his/her own prejudices and constructions of reality.

3.6. THE MILAN APPROACH TO FAMILY THERAPY

The researcher has chosen to describe her study as "systemic" as she has followed the theoretical viewpoints set out by the Milan family therapy team. The Milan team believe that they work from a "systemic" perspective as they have drawn from systems theory, cybernetics and information theory to establish their theoretical concepts. It is important to note that, "the Milan team view the world primarily as a system of patterns and information rather than as a system of mass and energy. Thus, they follow Bateson's (1979) ideas about systems rather than von Bertalanffy's (1968)" (Tomm, 1984a, p. 117).

3.6.1. Background information

In the late 1960s, Maria Selvini-Palazzoli, Luigi Boscolo, Gianfranco Cecchin and Guilian Prata were practising as psychoanalysts specialising in the treatment of anorexia and psychosis. Their unsuccessful attempts to apply psychoanalytic concepts to the family led them to realise that a new method of treatment which incorporated the family context in which the symptoms occurred, was necessary. It was at this stage that these four therapists formed the Milan team and evolved a systems approach to family therapy (Vorster, 2003).



In 1971, the Milan team began their transition to systems thinking by following the work of Haley, Watzlawick, Beavin and Jackson, along with others who represented the systems perspective of the Mental Research Institute (MRI) (Tomm, 1984a). Their therapeutic focus was on interactional patterns and pathogenic double-binds and made use of therapeutic interventions, such as prescribing symptoms and reframing (also known as positive connotations), in order to present the notion that symptoms were functional to a specific family, and thus should not be altered. Their basic premise was that symptoms were maintained through interactional patterns, governed by rules. Dysfunctional families, particularly schizophrenic families, are involved in covert "family games", or moves, in which family members try to control each other's behaviour in a unilateral manner and so the therapist's role is to discover and disrupt these "games" (Tomm, 1984a).

In 1978, the Milan team published the book *Paradox and Counterparadox*, in which they set out their working approach and, in particular, their unique model of managing therapy sessions. Their focal points at this stage were identifying patterns of interaction and family rules in the here and now and searching for a pathological homeostatic pattern, in order to change the pattern and transform the family. This change was brought about by the counterparadoxical intervention that was implemented to nullify the pathogenic double-bind that the families had brought to therapy. Another intervention employed by the Milan team was the family ritual, which was intended to address the family rules. This was done by giving the family members a new behavioural experience, clarifying these rules and clarifying confusion of logical levels, i.e. between verbal and non-verbal messages (Tomm, 1984a).

During this time the Milan group's work was more in line with strategic and thus first-order cybernetic principles, and taking an adversarial stance between the observers and observed. Later, their work shifted away from this perspective towards a second-order cybernetic approach, concentrating more on family meanings rather than behaviour and they also included the therapist as part of the therapeutic system (Becvar & Becvar, 2002).

Towards the end of the 1970s, the team were inspired by the work of Gregory Bateson (after re-reading "Steps to an Ecology of Mind and Mind and Nature"), and by the Haley versus Bateson debate on power issues (Tomm, 1984a; Vorster, 2003). They began to realise that their linear punctuations of the family, in particular their emphasis on control and the adversarial stance that they had adopted toward the disruption of the family game, was blinding them to the cybernetic circularity. Bateson's ideas brought them closer to a second-order cybernetic perspective and in 1980 they published the article, *Hypothesizing, Circularity and Neutrality: Three Guidelines for the Conduction of the Sessions*, which



marked their movement towards a more circular approach to family therapy, keeping their basic practice and management of the session largely unchanged. The difference was one of attitude and philosophy, rather than of strict practice (Selvini-Palazzoli et al., 1980).

Their key principles namely; hypothesising, circularity and neutrality (Selvini-Palazzoli et al., 1980) form the basis of this study and will be discussed in more detail in section 3.6.2.

Between 1980 and 1989, the four members of the Milan team split into two groups due to emerging differences in their thinking and practices, however, both groups retained similar systemic perspectives.

3.6.2. Understanding the key principles of the Milan approach

The Milan team was successful in establishing three principles that they considered indispensable for interviewing the family (Selvini-Palazzoli et al., 1980). These principles will now be discussed.

3.6.2.1. Neutrality

For the Milan group the concept of neutrality refers to a multi-positional stance in which the therapist is allied with everyone in the system and no one simultaneously. In other words all the members in the system are given equal weight and the therapist is on no single individual's side which implies that all assumptions and hypotheses are organized free of judgement. Therefore neutrality does not imply objectivity (Gelcer, McCabe, Smith-Resnick, 1991; Selvini-Palazzoli et al., 1980).

Tomm (1984b) explains this concept by stating: "Neutrality implies that the therapist takes a metaposition with regard to individual family members, to their patterns of interaction and to their beliefs" (p. 262). Thus, no single definition of the problem is accepted - the therapist refuses to accept the family's labelling of the identified patient as the only problem in the family, and the therapist resists the attempts of the members to be drawn into a coalition with other members. Instead, the therapist forms successive alliances with all and none of the members and all differences in perceptions are considered to be acceptable. By taking on a metaposition in relation to the family, and bearing in mind the circular interconnectedness of all the members' behaviours and ideas, the hypothesis itself is considered to be neutral, because it synthesizes all of the elements of the system.

By maintaining neutrality, Fleuridas et al. (1986, p. 115) point out that the family perceives the therapist as:



- Not taking sides with any member or subgroup.
- Allied to everyone and to no one at the same time.
- Non-judgmental and accepting of everything.

3.6.2.2. <u>Hypothesizing</u>

By Hypothesizing, the Milan group refers to "...the formulation by the therapist of an hypothesis based upon the information he possesses regarding the family he is interviewing" (Selvini-Palazzoli et al., 1980, p. 4).

For the Milan team the hypothesis is viewed as the starting point within a circular course of investigating the family's interrelational structure. Gurman and Kniskern (1991) describe the hypothesis as a means of organizing information that becomes available to the therapist in such a manner that it serves as a guide for the therapist when conducting a systemic interview. By using a hypothesis, a structure is given to the therapist which enables him/her to organise the information obtained from the family. In this manner, the therapist is able to focus on specific issues that arise and disregard meaningless chatter during the interview (Hoffman, 1981).

The hypothesis also assists the therapist to seek out new information about how the family system operates; the connecting patterns; what purpose each family member's behaviour serves; which rules govern and circumscribe each family members behaviour, and what role each of the family members plays in the context of their problems, both within and outside the family system (Gelcer et al., 1990). Furthermore, Hoffman (1981) states that the hypothesis also play a vital role in suggesting what the meaning of the symptomatic behaviour in the family at the time.

According to Fleuridas et al. (1986, p. 115) the purpose of a hypothesis is as follows:

- To connect family behaviours with meaning.
- To guide therapist's use of questions and order.
- To introduce a systemic view to the family and to enable the members to develop new, but related, views of their relationships, beliefs, and behaviours.

3.6.2.3. Circularity

The founders of the Milan team describe circularity as "...the capacity of the therapist to conduct his investigation on the basis of feedback from the family in response to the information he solicits about relationships and, therefore, about difference and change" (Selvini-Palazzoli, et al., 1980, p. 8).



Gelcer et al. (1990) stipulate that in family systems there are circular actions and reactions which very often become fixed and predictable. Thus, through circularity, it becomes possible to observe the actions and reactions by focusing on the interactions between family members within a family system.

Fleuridas et al. (1986, p. 116) explain the purpose of circularity as follows:

- To introduce the family to a systemic view of itself by providing new information about their concerns, beliefs, behaviour and relationships.
- To develop, confirm or deny the team's hypothesis about the family and the function of the problem.
- To intervene indirectly by raising issues neglected in the family (such as expressing appreciation, allowing independence, helping a child learn a desired trait through modelling) or by questioning the effectiveness of attempted solutions to their situations.

The Milan group introduced and made use of circular questioning as an interview technique to assess and elicit differences in relationships or differences in the perceptions of members within a family system. In so doing circular questions provide the space for the family to view itself systemically, thus, circular questions are "tools" used to scan for differences; they have the power to introduce differences which alter behaviour, thus changing relationships (Fleuridas et al., 1986; Selvini-Palazzoli, et al., 1980).

According to Fleuridas et al. (1986) circularity implies that behaviour and beliefs do not occur in isolation thus individuals are best understood within their interactional contexts. A comprehensive systemic view of the family looks at evolving relationships of family members within their environmental, historical, developmental and ideological contexts.

Furthermore this interview technique examines recurring contextual patterns of interaction which make up the family system by exploring the behavioural and ideological links between the development of the problem, changes in intra-familial relationships and interactions around these dynamics. Thus, circular questions are really questions which enquire about the relationships in the family (Fleuridas et al., 1986; Selvini-Palazzoli, et al., 1980).

This technique allows for each member of the family to give their opinion and experience of what they believe to be the family's presenting concern, the sequences of interaction which is usually related to the problem and the differences in relationships over time. This information will provide the family and therapist with a systemic picture of the problem – allowing the



therapist to generate hypotheses and create interventions, in order to interrupt the dysfunctional cycles of interrelating and challenge the family's beliefs (Fleuridas et al., 1986; Selvini-Palazzoli, et al., 1980).

It is also essential to remember, that, when conducting an interview in this manner, the therapist must implement neutrality and hypothesizing within their circular questioning process as these three principles work hand in hand (Fleuridas et al., 1986; Selvini-Palazzoli, et al., 1980).

3.7. CONCLUSION

A description of linear and circular perspectives has been outlined in this chapter, followed by the relevant systems terminology used in this study. A distinction between first-order and second-order cybernetics, which form the basis of the systemic perspective, were discussed. The formation and key principles of the Milan approach were also reviewed, including their renowned therapeutic tool: circular questions. Circular questions have been employed in this research as the data-gathering technique. These theoretical principles have been used in the implementation of the intervention with mothers and children and in the evaluation of the effectiveness of the intervention on mother-child relationships.

The following chapter presents a detailed description of the research process and related aspects that have been incorporated into this study.



CHAPTER 4 METHODOLOGY

4.1. INTRODUCTION

This chapter highlights the methodological procedures used in this study. An overview of the project will be given and will be followed by a systemic description of the intervention. The aims of the study, the research design and how the participants were selected will be discussed, within the context of the research. In addition, a description of how the data was obtained and analysed, as well as the ethical procedures taken, will be provided. Finally, the researcher's role and subjective experience will also be discussed.

4.2. BACKGROUND

The present study forms part of a larger study, namely the Kgolo Mmogo project, which is a five- year project. One of the goals of the project is to test the effectiveness of a mother-child intervention which is specifically focused on improving adaptive functioning and promoting the resilience of young children between six and ten years old whose mothers are HIV-positive.

The intervention required the mothers and their children to attend weekly support groups with other HIV-positive women and their children over a six-month period; 25 sessions overall. Initially, the mothers attended 15 sessions, each one covering a specific topic, for example: learning about HIV, "living positively", disclosure, effective parenting, coping, problem-solving and stress management, etc. The aim of the sessions was to develop parenting skills and improve mother-child relationships. In addition, the children participated in similar sessions with other children. The children's intervention was based on the needs of the children as well as guidelines from two existing programs: *Building Resilience in Children Affected by HIV/AIDS* (Mallman; 2003) and *A Guide to Promoting Resilience in Children: Strengthening the Human Spirit* (Grotberg; 2003b). It is important to mention that the children were not informed that the intervention was aimed at HIV affected families as many of the mothers were not ready to disclose their status to their children. Thus, the purpose of the children's sessions were not to educate the child about HIV/AIDS but rather to enhance his/her; sense of self, problem solving skills and life skills.



The last 10 sessions were joint sessions, where the mothers and their children were given the opportunity to engage in activities together. The purpose of the two interrelated components of the intervention was to provide support to mothers by addressing the psychosocial effects of the disease which include: decreased social support due to the stigma of the disease; increased rates of depression; poor self-esteem and avoidance coping. The intervention was also undertaken to improve the mothers' ability to communicate and interact with their children in an age-appropriate manner, thus enhancing the children's adaptive functioning and promoting resilience.

The aim of the larger project is to develop, implement and evaluate the intervention programme using an experimental design. If proven effective, this programme could be replicated in resource-poor communities in South Africa using trained volunteers as facilitators.

This research was conducted as part of the formative evaluation of the mother-child intervention which was incorporated into the pilot study at the Kalafong Hospital in Tshwane (South Africa). This study focuses on the description of family relationships, which was furnished by the mothers once they had participated in the mother-child intervention.

4.3. THE INTERVENTION IN TERMS OF THE THEORETICAL FRAMEWORK

In 2006, The Kgolo Mmogo project implemented a 25-week intervention programme, the aim of which was to help children build resilience. With enhanced resilience, children are better able to deal with future problems, especially when their mothers become ill or die, which may leave them in a vulnerable situation, for example, the children might have to take charge of the family, or they might have to take on day-to-day tasks that would normally have been taken care of by their mothers.

The intervention focused on various subsystems, specifically on the mothers, children and the combined mother-and-child groups. This research project punctuated the mother-child interaction by focusing on how the mothers viewed the intervention and on how the intervention impacted their relationships with their children.

From a systemic perspective, it is assumed that the facilitator is an observer of the various systems and their interactions (Boscolo et al., 1987). The designers of the intervention constructed weekly sessions which were structured around set psycho-educational themes and centred on the development of life skills. The primary focus of these skills was on



mother-child interaction, for example: parenting, discipline, problem-solving, and communication. It can therefore be said that the sessions aimed to communicate new information to the family systems (Keeney, 1983), which could be described as "meaningful noise" in Varela's (1981) terminology.

The systemic perspective asserts that knowledge is socially constructed through multiple truths (Maturana, 1978). As such, the psycho-educational aspects of the intervention were enriched by the participants' personal experiences. In other words, the intervention was not conducted solely on the basis of the facilitator's "expert knowledge"; the participants played a role in teaching each other, and consequently shared the "expert" position with the facilitator (Cecchin et al., 1994; Hoffman, 1990; Tomm, 1984b). This format was applied to the child, mother and combined groups.

In addition, the theoretical standpoints set out by the Milan school were incorporated into the research. The theoretical assumptions used during the research process were (1) that the family-defined problem, such as HIV, would determine the interaction in the family and (2) by perturbing the problem-determined system, (i.e. the family), through the intervention process, the mothers would be able to redefine their family interaction. In other words, the mother's HIV status influences the manner in which the family members interact and the whole family contributes to the perpetuation of this behaviour. Thus, the mother-child interaction intervention was introduced as an intervention strategy in order to initiate change within the family system.

The interaction between the various participants, and between the participants and the facilitator, in the sessions, allowed for the perturbation and the co-constructing of new realities to take place, not only within the group, but also within the individuals' interacting system outside of the group. In other words, the participants could verbally share what they had learned at the group sessions at home with their children and with other family members; if a change in the mothers' perception of behaviour had indeed taken place, this too, could facilitate change through the interaction patterns (Kenny, 1985).

4.4. THE AIM OF THE STUDY

This research project aims to describe families that are affected by HIV/AIDS from a systemic perspective. From this perspective, the assumption is that any behaviour displayed by one member of the family will affect the behaviour of the rest of the family members in a cyclic manner (Selvini-Palazzoli et al., 1978). In other words, the way in which the HIV-



positive mothers perceive themselves and the manner in which they behave will affect the rest of the family and vice versa.

This study aims to investigate (1) the effect of HIV on family interaction and (2) the effect of the mother-child intervention on family interaction from the perspective of the HIV-infected mother. Thus the project aims to answer the following questions: How do HIV-positive mothers experience their relationships with their children once they are diagnosed? And, how does that relationship change, if at all, after participating in a mother-child intervention?

4.5. RESEARCH DESIGN

This research was conducted by interviewing four of the mothers who had participated in the mother-child intervention. The interviews took place ten months after the intervention at the Kalafong Hospital. Having attended the intervention at the same venue, the mothers were familiar with their surroundings, and perceived the environment as being relaxed and non-threatening. Inviting the mothers to a secure setting encouraged them to disclose more information concerning their circumstances at home.

For the purpose of this study, a case-study method was used as a means of a qualitative research design, so that a substantial amount of information was generated about a few participants. This has allowed the researcher to gain greater insight into the subject that is being studied by focusing on the unique characteristics. In addition, the researcher anticipated that the findings could contribute to insight into other similar situations and cases. The implementation of case study methods allows for the findings to be easily understood by both academic and non-academic individuals as professional jargon has been omitted (Neuman, 2000; Nisbet & Watts, 1984).

However, there were limitations to the interpretation of findings from case studies, which need to be taken into account. Firstly, the findings cannot be generalized, since they indicate the experiences of specific individuals, and secondly, case studies are not open to crosscontrol, which can lead to selectivity, bias and subjectivity (Nisbet & Watts, 1984).

The fundamental assumption of qualitative research is that a better understanding of the client's world can be gained through observation and conversation in their natural environment as opposed to situations where experimental manipulation is conducted in artificial conditions (Anderson & Arsenault, 1998). In contrast to quantitative research where a formal and neutral tone with statistics is utilized, qualitative research contains rich descriptions, colourful detail and unusual characteristics (Neuman, 2000).



Willig (2001) states that a qualitative researcher is concerned with meaning and thus, is interested in how people make sense of the world and how they experience events. The aim of such research, therefore, is to obtain an understanding from the research participants as to what it is like to experience particular conditions and how they manage the situations that they find themselves in. In other words, qualitative researchers are concerned with the quality and texture of experiences and not the identification of cause-and-effect relationships. They are therefore interested in the meanings that participants ascribe to certain events, as well as to the interpretation they formulate with regard to their own experiences of events (Gerson & Horowitz, 2002; Willing, 2001).

The study is explorative and the questions were designed to contribute to a greater understanding of the phenomenon at hand. The research focuses on the person's subjective world, which has no meaning when generalizing, and is only valid within the confines of family system that is being investigated (Neuman, 2000).

It is also important to note that the obtained data was only the view of the mothers which means that this was only part of the "truth". The data reflected how the mothers found meaning in their understanding of what was happening in their relationships with their children (Becvar & Becvar, 2000). From a second-order and systemic perspective, it was a truthful construction of the mothers' own experiences that may not have been shared by other members of the family.

4.6. SAMPLE SELECTION

The mothers and children who participated in the intervention were recruited at the Immunology clinic at Kalafong Hospital, where they were being treated for HIV. The HIV counsellors at the clinic identified 20 HIV-infected African mothers with children between the ages of six and ten, and informed them about the research project. Mothers who consented to participate in the intervention were invited with their children to attend a series of 25 group sessions, each one focusing on various topics.

The twenty mothers were divided into two groups of ten, as were their children. The mothers and children were placed in separate groups initially, so that they could obtain information and skills that would maximize their interactions with each other in the joint sessions, and improve interactions outside of the intervention. The researcher facilitated one of the mothers' groups and later co-facilitated and observed the interaction between these mothers and their children in the combined sessions.



For the purpose of this study, a non-probability sample of four participants from one of the mothers' groups was used. The rationale for such a selection process was that researcher perceived the participants' experiences to be more relevant to the research topic than their representation to the general population (Flick, 1989, as cited in Neuman, 2000). Purposive sampling was utilized, as the researcher deliberately wanted to highlight the unique cases that were especially informative (Van Vuuren & Maree, 2002). The sample fell within a difficult-to-reach, specialized population, and the researcher feels that these particular cases would be an ideal way to investigate the influence of HIV on family interactions, as well as the feasibility on the mother-child intervention (Neuman, 2000).

Ten months after the intervention took place; the mothers chosen for this study were invited by the researcher to share their experiences of the intervention and to describe their relationships with their children both before and after the intervention. For the sake of continuity, the interviews were conducted at the same venue by the researcher who was also the group facilitator during the intervention. The researcher motivated the participants to take part in the interviews by offering them transport money and a meal. These incentives were also offered to the participants during the intervention by the principal investigators of Kgolo Mmogo.

Before the interview commenced, the nature of the study was explained to each participant. The participants gave full consent to the interview and permission for the interview to be recorded. In addition, they were informed that their participation was voluntary and were given the option to withdraw at any stage.

4.7. DATA COLLECTION PROCEDURE

A systemic approach was implemented throughout the data collection process and was based on the viewpoints of Selvini-Palazzoli et al. (1978) throughout the data collection process.

The researcher's process notes from the group sessions were used as a source of data to generate a hypothesis about the interaction between each mother and her child. In addition, the researcher reviewed and reflected on her process notes in order to determine the changes that might have taken place in the families during the time of the intervention process. One should bear in mind that these identified changes were based on the researcher's interpretations of what she perceived to be happening during the mother-child interaction.



Once the hypothesis was formulated the researcher began the interview process and implemented neutrality and circularity in order to collect the data (Fleuridas et al., 1986; Slevini-Palazzoli et al., 1980). The participants' stories were conveyed in a structured interview in which circular questions were utilized as a means to gather the data, and in order to describe certain relationship patterns which prevail in mother-child relationships.

The Milan group introduced and made use of circular questioning as an interview technique to assess and elicit differences in relationships or differences in the perceptions of members of a family system. In so doing, circular questions give the family the space to view itself systemically, thus, circular questions are "tools" used to scan for differences and also have the power to introduce differences that make a difference to behaviour (Fleuridas et al., 1986).

Even though circular questioning is often used in therapeutic interventions, it has also been used in research studies (Cecchin et al., 1992). These researchers argue that from a researcher's perspective, it was difficult for clinicians to distinguish between conducting therapy and conducting research as they were constantly aware of the effects of their own behaviour on their clients. Thus, their actions or interventions could be called research. Also, as researchers they could not avoid co-constructing a new reality with their participants, and thus became clinicians.

The circular questions examine recurring contextual patterns of interaction which make up the family system by exploring the behavioural and ideological links between the development of the problem, changes in intra-familial relationships and interactions around these dynamics. Circular questions therefore are questions which enquire about the relationships in the family (Fleuridas et al, 1986). This technique allowed the mothers to express what they believed was the family's presenting concern, as well as the sequences of interaction which are usually related to the problem and the differences in relationships over time. This information aims to provide the system and the researcher with a systemic picture of the problem – allowing the researcher to generate hypotheses and create interventions in the future, which will interrupt the dysfunctional cycles of interrelating and challenge the family's beliefs (Fleuridas et al., 1986).

The following are examples of circular questions used in this study:

- How was your relationship with your child/ children before you were diagnosed as HIV positive?
- How has HIV influenced your relationship with your child/ children?



- How was your relationship with your child/ children before you attended the Kgolo Mmogo project?
- Is it still like that?
- What is your explanation for the change / for it remaining the same?
- Who in your family would agree and who would disagree with you?
- What sense do you make of the way your relationship was with your child/ children at the time?
- How do you see your relationship with your child/ children to be in the future?
- Who was closest to whom in the family before the intervention?
- Who is closest to whom in the family now?
- Who was the least closest in the family before the intervention?
- Who is the least close now?
- Who spends the most time with whom?
- Who would be closest in the future?
- What is your reason for the likelihood that this would happen?

4.8. DATA ANALYSIS AND INTERPRETATION

Once the information was gathered and the data was transcribed, a detailed description, or punctuation, of the families and their emerging patterns was integrated by the researcher in line with a systemic perspective. The researcher looked at each mother's experiences individually and holistically, in the context of the intervention, and in so doing, searched for similarities and differences between the participating families, thus the study became descriptive in nature (Neuman, 2000). It is important to note that this is one of the possible perspectives of the study as shown by the researcher's own punctuation and interpretation of the participants and their circumstances.

The researcher has described each family system in terms of the following characteristics which were defined in Chapter 3:

- i. The system's components
- ii. Relationship styles
- iii. Family rules
- iv. Boundaries
- v. Power, alignments and coalitions
- vi. Circular patterns of interaction



vii. Evaluating the impact of the intervention on the system in terms of feedback, homeostasis and change

Furthermore, the impact of HIV on the family system was reviewed and the author's reflections, which form part of an observing system, were discussed.

The findings will be discussed in Chapter 6.

4.9. ETHICAL PROCEDURES

4.9.1. Permission

Permission to do the adjoining research was previously obtained from:

- 1. Tshwane Metro Health Services in order to conduct the research at the Kalafong Hospital.
- 2. Ethics Committee of the Health Sciences Faculty of the University of Pretoria and the Yale University School of Medicine.

Permission to do this specific research, in the form of four case studies was obtained from the principal investigators, Prof B.W.C Forsyth, from the Yale University School of Medicine and Prof I. Eloff, from the Education Faculty, University of Pretoria.

In addition the Ethics Committee of the Faculty of Humanities, University of Pretoria, granted ethical clearance for the present study.

4.9.2. Informed consent

Before participating in the intervention, the mothers gave their informed consent (Appendix A). The mothers were also asked to sign a letter of consent before the interviews were conducted. (Appendix B).

All information obtained about the subjects during the study was treated in the strictest confidence as part of the ethical responsibility of the researcher. However, the researcher needed to use the information disclosed to her to prove her existing hypothesis and research questions. To overcome this problem, the participants were informed of the nature of the study and consented to the disclosure of the information provided, on the condition that their identities were not revealed. They were also given the option to withdraw from the study if



they felt threatened in any way. Under no circumstances were the participants forced to take part in any activities that made them feel uncomfortable. In addition, if the participants had expressed a desire for a follow-up session, a referral would have been made to an appropriate service.

In the event that the findings are to be published in the form of a dissertation or research article, the identities of the mothers will not be made known.

4.10. THE ROLE OF THE RESEARCHER

During the implementation of the intervention, the researcher's role was that of a facilitator who aimed to facilitate change and to actively observe the mothers and their children in the group. During this time, the facilitator formed a relaxed and trusting relationship with the participants and reflected on various sessions in her process notes in order to familiarize herself with the participants' backgrounds. By taking on the role of facilitator, the researcher was an active participant in the intervention sessions. From a systemic perspective, the researcher was an observer involved in the process of observation within the system, implying that objectivity was impossible (Selvini-Palazzoli et al., 1980).

It is important to note that, from a systemic epistemology, objectivity is not synonymous with neutrality. For the Milan group, the concept of neutrality refers to a multi-positional stance in which the therapist is allied with everyone in the system and no one simultaneously. In other words, all the members in the system are given equal weight and the therapist is on no single individual's side. This implies that all assumptions and hypotheses are organized free of judgement. However, the facilitator is interacting directly with the participants which results in the subjective experience of the mothers and the difficulty they have concerning their HIV status (Selvini-Palazzoli, et al., 1980).

Ten months after the intervention was completed, the researcher's role changed from facilitator to interviewer. The researcher interviewed the mothers by means of circular questioning to explore the impact of the intervention on their relationships with their children (Fleuridas et al., 1986; Penn 1982). Here, the researcher and the participants were in constant interaction with one another. The researcher was thus subjectively involved in the process of data collection (Anderson & Arsenault, 1998). During the research process, it was vital that the researcher was conscious of her own assumptions and moral prejudices (Cecchin et al., 1994; Hoffman, 1988; 1991). The researcher had to set these prejudices aside, shift her focus on to the participants' perspective, and allow the participants' "voices"



to be heard (Gerson & Horowitz, 2002). She did this by being constantly aware of her subjective feelings and prejudices, ensuring that they neither influenced the research process, nor compromised the validity and reliability of the data (McMillan & Schumacher, 2001).

According to Schurink (1998) "the observer must attempt to mentally operate on two different levels: becoming an insider while remaining an outsider" (p. 283). The researcher made every effort not to become too involved with, or distance herself from, the real meaning of the participants' social reality. For this reason, the task of the qualitative researcher is a difficult one, as the researcher treads a fine line between being involved and remaining unbiased (Gay & Airasian, 2003).

4.11. REFLECTING ON THE RESEARCH PROCESS

As a counselling psychology student, the researcher began her journey with the Kgolo Mmogo project by helping write the manual for the intervention. This allowed the researcher to feel like she was part of the project and helped her understand what was expected in the sessions. During this process, the researcher was given the opportunity to satisfy her desire for knowledge, as she worked closely with the other members of the project and learnt from her seniors. This process also helped the researcher realise her capacity for creativity and she felt that she could contribute to those in need by using this talent.

After a lot of hard work, the researcher began the second phase of her journey by facilitating one of the mothers' groups in June 2006. Not having conducted groups sessions before and having only experienced individual therapy, she found this very challenging, as her attention had to remain focused on all ten group members at the same time.

Having acquired new skills in her course i.e. circular questioning, the researcher began to implement this technique into her facilitation with the group. It was here that the researcher began to understand the value of this type of questioning and was prompted to investigate this technique further.

The researcher was also confronted with language and cultural barriers during the intervention. At first, the researcher struggled to facilitate the group as she had not worked with a translator before. She soon came to depend on her co-facilitator as she played a valuable role in translating what the mothers had said during the sessions. This process built



trust amongst the two facilitators and a good working relationship emerged. Later, the same translator assisted the researcher during the data collection process.

During the group sessions, the researcher enjoyed educating the mothers on various aspects, but felt as though she did not have sufficient time to discuss other aspects that would emerge in the course of the session, for example, when discussing the stages of bereavement, it was difficult not to allow the women to describe their personal experiences. Having taken this issue to supervision, the facilitator realised that she needed to present the information to the mothers in the available time and decided to make herself available after the sessions, should the mothers need to discuss a personal issue further. This approach created more trust amongst the group members and the facilitator. It also helped convey the researcher's caring and approachable persona. Occasionally, some participants did request individual attention and this enabled the researcher to get to know the women better.

Overall, the researcher learnt more from the group than she had anticipated. Not only did she learn how to facilitate groups, she also realised that the relationship between therapist and client is not a one-way process. The researcher learnt that clients have the capacity to greatly impact a therapist's life, and can give one cause to reflect on one's own life experiences. In addition, the researcher learnt that groups, just like families, are able to sustain themselves and to nurture their own needs, by being nudged or perturbed by a facilitator.

During the sessions the researcher was inspired by the mothers' stories and she also felt honoured to have been able to witness and play a part in the interactions between the mothers and their children. Thus, she began the third phase of her journey, subsequently, after the completion of the 25 week sessions. The researcher felt that the women that had impacted on her life should be given a voice so that they could be heard and commended for their hard work, dedication and will to survive. In addition, she wondered if such interventions were of value to the mothers and began to evaluate the project by hearing from the mothers themselves, what they felt and how this project had impacted on their relationships with their children.

While writing her thesis and reflecting on the findings and research process the researcher was surprised at how engrossed and personally affected she had become by the research. The literature and theory that she had spent hours intermingling with had come alive. Like a living being it grew bigger and bigger and was viewed by the researcher through a set of different lenses during her interactions with the participants. The circular questions that were



used during the interviews elicited a deeper voice from the participants as their stories intensified as they generously shared their personal struggles and heartening moments. While living with fear and uncertainty brought upon by HIV, it was undeniably elevating for the researcher to bear witness to the participants' ability to find meaning and purpose in life.

4.12. CONCLUSION

This chapter outlines the methodology followed in the research study. An overview of the project was provided and was followed by a systemic description of the intervention. The aims, the research design of the study, and how the participants were selected were discussed in detail. In addition, the procedures of data collection and methods of analysis were thoroughly discussed. The researcher's dual role as researcher and group facilitator was explained. The researcher's subjective experience during both role processes was also described.

The researcher followed the systemic viewpoints as laid out by the Milan School, describing the families and their emerging patterns. The findings derived from the above method will be presented in the next chapter.



CHAPTER 5 FINDINGS

5.1. INTRODUCTION

This study was conducted to assess whether HIV-positive mothers experienced an improvement in their relationships with their children, after participating in a mother-child intervention.

In this chapter, the data is presented in the form of case studies wherein a detailed systemic description was used to describe the participants and their families. The participants' stories were conveyed in a structured interview in which circular questions were utilized. In addition, the researcher also referred to her process notes that were made when she facilitated the mothers' groups and mother-child groups during the intervention. The names of all involved have been changed for the purpose of anonymity.

The researcher will introduce the participants and their families to the reader by recounting the participants' background information and the various systems' components. Their relationship styles, family rules, boundaries, power, alignments and coalitions, as well as the family's circular patterns of interaction are discussed so that a richer understanding of each family's unique make-up or structure is obtained. Furthermore, the author interwove the information pertaining to the participants' families of origin with the current information pertaining to their nuclear families to create a clearer picture of the family dynamics, and to illustrate where some of the behaviour originates.

In addition, feedback, homeostasis and change are used to evaluate the impact of the intervention on the family system. In order to acquire insight into how the mothers experience their relationships with themselves and others, the impact of HIV on the family before and after the intervention is explored. The author's reflections, as an observing system, are discussed in accordance with a second-order cybernetics stance.

Next, the current study findings will be summarized and discussed in terms of the participants' similarities and differences. Thereafter, these findings will be put into perspective, in relation to the reviewed literature.



5.2. CASE STUDY ONE - Phumzile

5.2.1. Background information

Phumzile is a 46-year-old widow whose husband, Silo, passed away from AIDS. She currently lives with her four children and two grandchildren in Atteridgeville.

In the late 1990s, Phumzile discovered that her husband was having an affair. She was deeply saddened and hurt by this revelation, as she never thought that Silo would engage in such behaviour. She always believed that she had a happy marriage and that Silo was trustworthy. Phumzile described her husband as a quiet man who did not gamble, drink, and smoke or have many friends.

Prior to her discovery, Phumzile was content with her marriage partner. According to Phumzile, Silo was a homebody who did not spend his money frivolously and Phumzile believed that he always put his family first.

In 2001, Silo became very ill and started staying away from work. When Silo became bedridden, Phumzile tended to him. During this time, Phumzile noticed that Silo had lost a great deal of weight and that his appetite had diminished. She also noticed that he had sores on his skin. Silo's mysterious illness troubled Phumzile, and she started to wonder whether Silo was HIV-positive. Phumzile tried to convince Silo to seek medical attention, but he refused. After much deliberation, Phumzile decided to undergo an HIV test, only to discover that her worst fears had become a reality.

5.2.2. The system's components

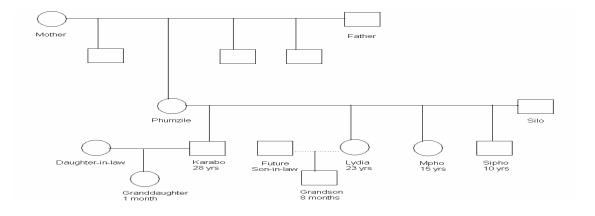


Figure 3: Phumzile's genogram



Phumzile has three brothers, two of which, are younger than her and her parents are alive and still married.

Phumzile and Silo have four children, two boys and two girls, ranging in age from 10 to 28. All four children currently reside with their parents. Their oldest son, Karabo, is married and has recently had a baby. Phumzile explained that her daughter-in-law and her grandchild were staying at her daughter-in-law's parent's house for the duration of the 30-day maternity period, in accordance with tradition. Both her daughter-in-law and her grandchild will move in with Phumzile once this period has ended. The oldest daughter, Lydia, is engaged and has an eight-month-old baby with her fiancé. Mpho and Sipho are still in school.

After Silo passed away, Karabo moved back home and became the head of the family. Phumzile now relies on Karabo to support the family financially and to set an example for his younger siblings, while she takes care of the household duties. She is pleased to have all her children and her grandchild living with her. She is also extremely excited that her daughter-in-law and other grandchild will be moving in soon.

The family members mentioned above make up the various subsystems within Phumzile's family.

In Phumzile's family of origin, her mother and father make up the parental subsystem and Phumzile and her brothers make up the sibling subsystem. For the purposes of this case study, these subsystems will be referred to as the extended family subsystem.

When Phumzile and Silo got married, they formed the couple subsystem. Later, when they had children, they also became members of the parental subsystem. Their children make up the sibling or children subsystem, and their children's spouses make up the extended sibling or extended children subsystem. Karabo's child and Lydia's child make up the grandchildren subsystem.

5.2.3. Relationship styles

Phumzile believed that she and Silo had a symmetrical relationship wherein they both displayed similar behaviour. She believed that they were both quiet, yet assertive individuals who contributed to the family equally. Silo would work and provide financially for the family, while Phumzile stayed at home and took care of their household and children. In Phumzile's



opinion, neither of them felt that the other was more dominant, and she believed that they shared the same beliefs, values and views which they tried to instil in their children.

However, once discovering that her husband was having an affair, Phumzile realised that she held a submissive position in their relationship. Phumzile felt as though Silo manipulated his work situation by telling Phumzile that he was required to work double shifts and in so doing was able to continue his affair while she was expected to remain at home. Phumzile also felt that she was not given the choice to protect herself during sexual intercourse as she was not aware of her husband's infidelity.

From the interview with Phumzile, it is evident that, while her children were young, a complementary relationship existed within the parental subsystem. The children were taught that there is a difference between their subsystem and their parents' subsystem. For example, the children were taught that they had to listen to their parents and do as they were told. However, once the children reached adulthood, they entered into a symmetrical relationship with the parental subsystem. For example, Karabo is now seen as a parental figure by his younger siblings. His siblings show him the respect that they would show Phumzile and Silo, in turn Karabo supports his siblings in the same manner in which his parents supported him and their other children.

5.2.4. Family rules

A few family rules were identified, depicting the manner in which Phumzile's family function.

i. Be proud of who you are

After the intervention Phumzile became proud of the person that she is and does not feel that she should be ashamed of herself because she is HIV-positive. She believes that her status should not determine who she is, and feels content that she has disclosed her status to her children and extended family members. Phumzile is a role model to her children, and they too believe that they should be proud of who they are.

They are all able to continue with their daily activities, despite what others may think. For example, in the past when they had people visiting them at home, the children would still remind Phumzile to take her antiretroviral medication. In addition, her children tell her constantly that they love her the way she is.

ii. <u>Family affairs are private</u>. However, outsiders may be informed of certain aspects, such as HIV, for educational purposes

Everyone in the family system knows about Phumzile's HIV status. However, her future son-in-law does not know about her status as he is not yet a member of the family. Phumzile said that when he is married to her daughter, she will inform him.

Phumzile has also told some individuals outside of her family system about her status, but is selective about who she tells. She has only told people who she is extremely close to, such as her friends and the mothers at the intervention. She has also disclosed her status to people that she feels need to learn about HIV, such as other women in her community who have been diagnosed with HIV or who have a family member who is HIV-positive.

Phumzile has placed valuable documents and information in a memory box¹ that she and Sipho, (her youngest son), made during their time at the intervention. The documents include the title deeds to her house, birth certificates, account numbers etc. Phumzile has informed her children about the memory box, and she has told them where they can find it once she has passed away. She has also told them that they are the only ones that should look at the contents of the box, and that they should not show or tell anyone about it for security reasons.

iii. Family members need to take care of each other

Despite her anger towards her husband, Phumzile took care of Silo when he was ill and bedridden. After Silo's death, Karabo moved back home and took on the father figure role and supports the family financially.

Phumzile relies on Karabo and Lydia to help make family decisions and hopes that they will look after their younger siblings, should she pass away.

Phumzile's youngest brother and sister-in-law also adhere to this family rule. They regularly check up on her and her children, and they purchase vitamin tablets and medication for Phumzile every month.

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¹ a safety deposit box designed to store important items



iv. Support is important

Supportive behaviour is important in this family system. Phumzile believes that she would not be able to carry on were it not for her children encouraging her to do so. During the interview, she said: "When I was ill in hospital, my children would visit me and did not turn their backs on me".

Phumzile's children and extended family members have encouraged her to look after herself and they tell her that she is an example to other HIV-positive individuals as she is able to keep herself healthy and strong.

This rule, however, does not apply to Phumzile's in-laws. Phumzile's in-laws are not supportive of her or of her children; Phumzile does not classify them as family and refers to them as her husband's family.

v. Open communication is important

Phumzile believes that it is important to communicate openly with her children and encourages them to discuss things amongst themselves or with her should they be experiencing a problem. It is for this reason that Phumzile has told her children about her status. She believes that they should know what is wrong with her and how they should care for her, if she is ill.

vi. Children are never too young to know what HIV is

Phumzile does not believe that her youngest son is too young to know about HIV. She believes that even though Sipho is ten years old, he should be educated about HIV. She considers HIV to be an important aspect of her life and wants her children to understand what she is going through. She added that Sipho has been showing an interest in HIV and has been seeking more information of his own accord. He has been watching documentaries and programmes about HIV, for example *Soul City* and *Isidingo*, and he has been paying attention at school where he is being educated about HIV. In their time together, Sipho shares what he has learned with his mother.

Furthermore, Phumzile feels that HIV is a phenomenon that is spreading throughout Africa and that her children should understand the implications of this illness just as they should know about other world issues. Phumzile is of the opinion that it is vital to educate others about HIV, and thinks that one should start by educating one's children first.



vii. Becoming an adult earns you respect and authority

In this system, the members of the children subsystem are aware of the differences between their subsystem and the parental subsystem. Consequently, they are taught to respect and honour their elders. However, when the children reach adulthood, an overlap occurs between the two subsystems. For example, even though Karabo and Lydia are part of the children subsystem, they are also seen as equal members of the parental subsystem. The younger children show their older siblings the same respect that they would show their parents as they view them as authority figures.

viii. Customs, traditions and religion are important

Customs and traditions play a vital role in this system. For example, after Karabo's wife gave birth, she was expected to stay with her mother for the first month so that she could be looked after and assisted. Lydia's fiancé is not allowed to stay with her until they are married, despite the fact that they already have a child together. As a married woman, Phumzile was meant to obey her husband and do as she was told. Her duties as a mother and married woman were to stay at home and look after her husband and children.

This family also views religion as being an important part of their lifestyle. Phumzile and her family attend church every Sunday. They also pray and play gospel music at home on a regular basis. Phumzile recalls becoming closer to God while she was in hospital: "I would see some people sleeping next to me; they were dying...I was so scared that I didn't sleep and then I started to pray, and when I started praying I could hear the voice of my granny, she was not there, she was dead. She would say to me: "Be strong, don't come to me. Go to your children. Your children are still young. Go look after them... When I come from those people I was just telling my children to go to church really because I did hear my granny telling me to go to church".

5.2.5. Boundaries

The system has always had clear boundaries in place between the parental subsystem and the children subsystem. The parental subsystem is firm, for example the children have to obey and respect their parents. But, the boundaries are also flexible in that they encourage a free flow of open communication between the two subsystems. This creates an environment where all the members in the system feel a sense of belonging.



The same boundaries seem to have been implemented between Phumzile and her parental subsystem.

Before the discovery of the affair, Phumzile and Silo also made use of clear boundaries. However, when Phumzile found Silo and his lover together, she lost respect for him and rigid boundaries were instituted between the two of them. Phumzile said: "Before, we were not fighting...so since then I did not behave nicely to my husband...all the time when he asked me something, I would tell him to go ask her, because I was so cross".

When Silo became ill and bedridden Phumzile continued to care for him, thus underlining the fact that the unwritten rule, "Family members need to take care of each other", formed the basis of the system's boundaries and determined the interaction between the members of the system.

It is interesting to note that the unwritten rule, "Becoming an adult earns you respect and authority", as mentioned above, allows the members of the children subsystem to move between their subsystem and that of the parental subsystem once the children become adults.

Overall the system can be described as negentropic, as there is a balance between openness and closedness, i.e., there is a balance between the information that enters and leaves the system. This is evidenced by the external environment that Phumzile interacts with, i.e. she is able to disclose her status to others in her community who would benefit from hearing about her experience without feeling judged.

5.2.6. Power, alignments and coalitions

Phumzile described her relationship, prior to the discovery of her late husband's affair, as a close relationship, in that they did not fight or feel inferior to one another. Phumzile stated that their "…relationship was very nice – he was a loving husband".

However, once she discovered that her husband was having an affair, Phumzile felt betrayed and hurt as she never expected that he would do this to her. It was at this point in the relationship that Phumzile began to feel that she was in a submissive role in the relationship and that Silo had all the power.



As a traditional black woman she stayed at home to care for her husband and children and "never had boyfriends". She felt that she had kept her end of the bargain, but that Silo did not keep his. Phumzile felt that she was unable to leave Silo because of cultural and traditional beliefs; also, she was not in a financial position to raise her children on her own. Phumzile found herself in a power struggle. She would try and get her power back from Silo by disobeying him when he would request something from her, but ultimately felt that she was unable to leave him.

However, Phumzile did manage to regain some power when she confronted Silo's mistress and showed her, her marriage certificate. This confrontation resulted in the other woman admitting that she was not aware of Silo's marital status and she promised to leave him.

In addition, when Phumzile found out that she was HIV-positive, she was very upset and again felt that Silo had the upper hand in their relationship. This angered her even more than the affair did. Phumzile became resentful of her husband and began to distance herself emotionally from him. In order to show her anger, Phumzile decided to stop speaking to Silo. She would only converse with him when she was tending to him, as she felt that she had to carry out her responsibilities as a wife.

Phumzile emphasized that she is close to her extended family (i.e. her parents and siblings) and that they are always supportive of her, unlike her husband's family. She also said that before she came to the intervention, she was closest to her youngest brother and his wife.

Phumzile states that her three youngest children were always closer to their father than they were to her. She added further that the three of them would often get upset with her when she spoke rudely to their father. Phumzile often felt that when she would reprimand Sipho, he would be supported by Silo. She felt that she had no support from Silo when it came to disciplining.

Karabo, however, was always very supportive of his mother and would often show his anger towards his father. When Silo became bedridden, Karabo took charge of the household, thus demonstrating his power in the family. For example, when Silo started coughing, Karabo demanded that Sipho, who was five years old at the time, stop sharing a bed with his parents. It was also at this time that Karabo took over the family's financial affairs and began making decisions for his younger siblings and mother. He instructed his mother to take his father to get medical attention and he asked Hospice to come to their home to help his mother tend to his father.



Initially, when Phumzile found out that she was HIV-positive, her children "were very ashamed of [her]" and perceived her to have done something immoral to have contracted HIV. This made it very difficult for her to connect with them once their father had passed away. Even though Phumzile's youngest daughter (aged 12 years at the time) would tend to her when she was ill and helped manage the household, it was only when Phumzile came to the intervention and learnt how to educate her children about HIV, as well as how to interact with them, that they became closer to her.

At this stage of her life, Phumzile feels that she is now close to all her children, but she is closest to Sipho emotionally. She attributes this to the fact that both of them attended the intervention. She believes that the intervention helped create a close bond between them, and that this relationship has been the modelled to her other children thus aiding to improve her relationships with her other children.

Phumzile also feels that her mother has become more supportive as she visits her frequently. She attributes this to her parents, especially her mother having always encouraged her to speak openly about the things that trouble her. Phumzile has taught her children to do the same.

5.2.7. Circular patterns of interaction

Prior to the intervention, Phumzile acknowledged that the angrier she felt about her status, the more hostile she became towards Silo. Her hostility prompted him to grow quieter, and the quieter he became, the more hostile she would become. Subsequently, the more they reacted in this manner the more her children empathized with their father and the less they empathized with Phumzile. In turn, this made Phumzile feel that they were ashamed of her, and that they loved their father more, causing her to distance herself emotionally from her children and her husband; as a result, they interacted less with her. The more this occurred, the more isolated Phumzile felt and the more her family did not know how to relate to her, and they interacted more with each other than with her adding to her feeling more that they were ashamed of her and so the circle would continue.

Phumzile felt helpless and frustrated that she did not know what was wrong with her husband or how to care for him properly. As a consequence, she would shout at her children in order to let off steam. This also added to circular interaction between her and her children i.e. her shouting in turn would lead to her children not knowing how to relate to her, which in turn



would add to Phumzile feeling more that her children where ashamed of her and she would feel more isolated and frustrated etc.

Being the youngest, and because he spent the most time at home, Sipho bore the brunt of most of his mother's frustration. He also did not comprehend what was happening, and thus withdrew from his mother and sought refuge in his room. His room was also his parents' room, so while his mother was busy in the kitchen, or attending to the rest of the house, he would spend more time with his father. So when Phumzile would shout at him, Sipho would withdraw from her and interact with his father. This led Phumzile to believe that Sipho was being disobedient and she would voice her frustration by continuing to shout at him.

After the death of her husband and before the intervention, many of the above interactions were maintained. Silo was still seen to be an absent, but present, member of the family. Despite the fact that Silo had passed away the members would still make reference to him in their interactions. For example Phumzile would still get angry with Silo and would continue to shout at the children as a means to relieve her stress, in turn the children would withdraw from her and the above mentioned cycle would continue thus the family maintained their interactive behaviours accordingly.

During the intervention, Phumzile learnt how to manage her stress and how to become more accepting of herself. The intervention also taught Phumzile and Sipho how to relate to one another, and how to spend time with each other. Not only did they continue these activities after the intervention, but they also introduced these activities into the system. The more time Sipho and Phumzile spent together, the closer they became. This interaction encouraged the other members of the family to react in the same manner.

5.2.8. Evaluating the impact of the intervention on the system in terms of feedback, homeostasis and change

Phumzile believes that the intervention has had a profound influence on her relationship with her son and has influenced their lives positively. Phumzile commented: "My everything! You know my everything has changed. I think it is the lessons we did here, because that is why we are very happy now, because we learnt to know each other and I have learnt also to know my child. I don't shout any more and I have time for my child when he asks me something and we can joke about something and we can talk about that thing."



Phumzile has also noticed how her relationship with Sipho has had a positive impact on the other members in the family system. She believes that even though her other children are much older than Sipho, they have learnt how to interact more freely with her and with each other. She remembers a time when she felt emotionally distant from her children and attributes this distance to the hostile feelings that she had towards Silo, as well as to the family's reaction to her disclosure of her status. Before coming to the intervention, Phumzile stated that her children were ashamed of her. "When we were looking at the TV, and looking at something about AIDS, I saw them, they were not happy, but now since I came here to the support group, they are very happy. I think it is the medicine that I have found here that has changed me and in changing me I have changed my family".

On a personal level, Phumzile feels that she has become more self-accepting and confident, and is also more equipped to deal with her stress. She no longer feels judged by her children and other members of her community. She is now able to control her temper and is less likely to shout at her children when she feels overwhelmed.

Prior to the intervention, Phumzile was afraid that she was going to get ill suddenly, suffer for a long period of time, and die like her husband did. However, after attending the intervention, Phumzile understood that if she continues to take care of herself, and continues to take her medication, she will likely live for a long time.

Phumzile has also found meaning in her life; she now lives for her children and grandchildren. Phumzile said to the researcher: "I told my children: 'Don't worry I am going to be here for 2010. I am going to watch the soccer'. And my dream was to see my grandchild, and I did see my grandchildren. I want to see Sipho's child too – I dream about that – I keep dreaming".

Phumzile believes that her children and extended family members have also noticed these changes.

Overall, Phumzile is delighted with the changes that have taken place and feels "free" now that she and her children have accepted her status and learnt more about HIV and AIDS. "I feel like I am born new – I am born again," she enthused.

The systems have not altered their values, traditions, customs and beliefs. These have been maintained as a way of creating order in the system, and to bring the members closer together, for example, going to church together as a family every Sunday.



5.2.9. The impact of HIV on the Family System

In the beginning, HIV came between Phumzile and the rest of the family members. Phumzile was very angry with Silo after the discovery of her illness. She distanced herself emotionally from him. Her children felt ashamed of her when they learnt about her status, as they did not understand how she had contracted HIV. Paradoxically, becoming HIV-positive has actually strengthened Phumzile's relationship with her extended family.

After the intervention, Phumzile became more accepting of herself, and no longer defines herself in terms of her status. She feels more equipped to discuss the repercussions of the virus with her children, and better able to educate them about HIV. She no longer wants to live a shameful life, but rather a life she and her children can be proud of. HIV now plays a more constructive role in Phumzile's life; it has helped her plan her future and that of her children and grandchildren.

5.2.10. Reflections from the observing system

As a researcher and facilitator, the author saw Phumzile as a friendly, happy and optimistic individual. Right from the very beginning, Phumzile demonstrated her willingness to learn and change the areas of her life that she was not pleased with.

Phumzile joined the mothers group in the eighth session. This made the facilitator question whether the group would accept her or whether she would be rejected, as they had already developed a rapport.

It was interesting to note how Phumzile shifted the dynamics of the group. Up until Phumzile's arrival, the members in the group were very quiet and spoke only when addressed individually. Phumzile introduced the following unwritten rules into the group: "It is acceptable to share personal stories so that we can learn from each other" and "It is acceptable to ask questions so that we can learn more about HIV/AIDS". In so doing, Phumzile proved to be both a role model and a leader in the group.

From the time Phumzile joined the intervention until the end of the intervention, her perception of herself had changed dramatically. She had become more confident and self-accepting and everyone in the group noticed this change.



During the combined sessions, Phumzile was very nurturing towards her son and was more willing to engage in playful activities compared with the other mothers. Her behaviour was, once again, an example to the other mothers. Furthermore, her determination to strengthen her relationship with Sipho, was evident.

As a woman, the facilitator/researcher found Phumzile's story to be very touching, as she is opposed to infidelity. However, she was inspired by Phumzile's optimism and determination to survive. The facilitator/researcher was constantly aware of her personal prejudices which prevented her from aligning with Phumzile in the system.

It was also rewarding to hear about, and observe, the various changes that Phumzile and Sipho had endured and how they were also able to facilitate change in their family system.

5.3. CASE STUDY TWO - Kgomotso

5.3.1. Background information

Kgomotso is a 36-year-old dressmaker who also works part-time as a domestic worker in order to earn an extra income.

Kgomotso grew up with her siblings, her mother and her mother's boyfriend. Kgomotso's mother was physically abusive towards her and her siblings. According to Kgomotso, her mother would often take out her frustration on her children by beating them, for no apparent reason. In addition, she would often leave Kgomotso and her siblings alone at home for long periods of time. Once, Kgomotso's mother left her children with her boyfriend, who attempted to rape Kgomotso; however, he was unsuccessful. Kgomotso's mother and her boyfriend separated shortly afterwards.

On another occasion, Kgomotso's mother left the children alone and social services intervened. Kgomotso, (who was fourteen years old at the time), and her siblings, were removed from their home and placed in a place of safety. After several weeks Kgomotso's aunt had found them and it was at this stage that her aunt was awarded custody of Kgomotso and her siblings. Kgomotso's relationship with her aunt began to strengthen at this point. Kgomotso is still angry with her mother for not coming to find them.

Kgomotso and her husband, Melusi, have recently separated and are in the process of divorcing. They have two daughters, Neo, aged eleven and Nomsa, aged three. Kgomotso also has a fourteen-year-old daughter (Thuli) from a previous relationship.



Prior to the completion of the intervention, they all lived together at their home in Atteridgeville. Kgomotso and Melusi's marriage was marked by constant fighting. According to Kgomotso, Melusi would often become physically and emotionally abusive towards her. Kgomotso would often fight back in order to protect herself. These violent outbursts would often take place in front of the children, but were never directed at them.

Now that she has separated from her husband, Kgomotso is concerned for her daughters' safety as Melusi broke into their house recently. He destroyed all of Kgomotso's personal belongings, including a wedding dress that she had made for a client. Kgomotso believes that Melusi could be a danger to their children, so she sent them to stay with her aunt in KwaZulu-Natal, as her aunt's house is unfamiliar to her husband. Kgomotso believes that her aunt is the best person to look after her children.

Kgomotso is currently living in her home with her mother. She finds this living arrangement stifling as she feels that her mother takes advantage of her. Kgomotso said that she has allowed her mother to stay with her because she feels sorry for her. Her mother, who lives in Hammanskraal, recently found work in Atteridgeville, and travelling from Hammanskraal to Atteridgeville every day is a long and costly journey.

5.3.2. The system's components

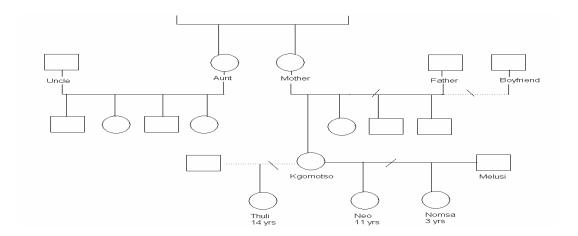


Figure 4: Kgomotso's genogram

In Kgomotso's family of origin, she was the first-born. Her father left when she was very young. Her mother never re-married but, for a period of time, she allowed her boyfriend to stay with them. Kgomotso's maternal aunt and uncle play a vital role in her life and she views this couple as her parental figures.



Before marrying Melusi, Kgomotso was involved in another relationship which resulted in the birth of her daughter, Thuli. She and Melusi have been married for twelve years and are in the process of divorcing. They have two daughters. This family can be described over three generations. In the first generation, or in Kgomotso's family of origin, her mother and father make up the parental system. This system is a broken system and does not play much of a role in the way Kgomotso views family. Her mother's sister and brother-in-law form part of the maternal sibling system. However, Kgomotso views this couple as her parental system. For the purposes of this study, the two systems will be referred to as the biological parental subsystem and the adoptive parental subsystem or extended relative subsystem.

The second generation is also made up of various subsystems. In Kgomotso's family of origin, she and her siblings make up the sibling subsystem, and her cousins, from her adoptive parental subsystem, make up the cousin subsystem. Kgomotso views all her siblings and cousins in the same way and for the purposes of this description, the two subsystems will be referred to as the sibling subsystem. Furthermore, Kgomotso also forms part of the couple subsystem that she and Melusi belong too.

Kgomotso's daughters, who are from the third generation, make up the children or grandchildren subsystem. From the children's perspective, the members of the first generation make up the grandparent subsystem. The mother's siblings make up the maternal sibling subsystem and the Kgomotso and Melusi make up the couple or parental subsystem.

5.3.3. Relationship styles

Since childhood, Kgomotso has had a complementary relationship with her biological mother; her mother has always been autocratic and domineering, and Kgomotso has always been expected to be submissive. For example, Kgomotso mentioned that she is expected to provide food and purchase electricity and telephone vouchers. However, when the resources run out, her mother leaves and returns to her home in Hammanskraal. This frustrates Kgomotso and she feels that her hospitality has been taken advantage of, but she is not able to tell her mother that she also needs to contribute to these expenses. Kgomotso believes that in order for them to get along, she should remain quiet and submissive.

Prior to the intervention, Kgomotso and her daughters also had a complementary relationship. Kgomotso stated that she did not know how to "handle [her] children". She stated further that her biological "mother was harsh and that is how [she] thought it should



be". As an adult she expected her children to "listen to [her], [she] is the one that says everything and knows everything".

After attending the intervention, she realised that she needed to change her approach so that she and her daughters could become closer. She explained that they now have a parallel relationship: Kgomotso allows her children to explain things to her and to take charge at times and at other times she is in charge. She has realised that her children should be able to voice their opinions, even though she may not agree with them; at times, they are able to discuss things openly.

Kgomotso and Melusi had a symmetrical relationship wherein they were both dominant players in their system. Financially, they both contributed to the system and both were decision-makers. However, they both competed for the position of leader in the family. Kgomotso also felt that Melusi was not an equal partner in their relationship as his contributions were not equal to hers. She claimed that she would often find herself in a difficult situation as a result of Melusi's actions. For example, her salary went towards the household bills, while his weekly wages were spent mostly on himself. These issues often led to verbal and physical fighting.

5.3.4. Family rules

A few family rules were identified, depicting the manner in which Kgomotso's family function.

i. In the past children were meant to be seen but not heard

As children, Kgomotso and her siblings were not allowed to voice their opinions or clarify their actions to their mother or to other adults. Kgomotso mentioned an incident that occurred many years ago, where she was washing dishes at the outside tap, whilst her baby brother was crying on her back. When she came into the house her mother shouted at her for not answering when she called her. Kgomotso tried to explain that she could not hear her because she was far away and her brother was crying. Her mother was very angry and threw a bone at her which cut her on her eyelid. Her mother told her never to talk back to her again.

Kgomotso carried this rule into her nuclear family. She expected her daughters to listen to her without talking back to her.



ii. Children have voices that must be heard

After attending the intervention, Kgomotso realised that she needs to listen to her children as they also have needs. She now sees them as "little people" who can teach her things, such as patience, and who can support her in her time of difficulty.

She encourages them to speak to her about things that are bothering them and to come to her when they are experiencing difficulties. Furthermore, she believes that "working (communicating) with your children is a really good method to raise your children" and that, "hitting them and shouting at them doesn't work". She added that this does not mean that she does not get cross with her children, rather she has learned that speaking to them and allowing them to be heard helps everyone involved to see things from the other person's perspective.

Kgomotso states that by not allowing her children to tell her their side of the story, she's liable to jump to conclusions and reprimand them unlawfully, making her unapproachable.

iii. Being an adult does not mean you know everything

This rule relates to the previous two rules. In the past, Kgomotso was under the impression that as an adult one knows everything and must always be obeyed: "My way was the only way," as Kgomotso put it. After the intervention, she realised that her daughters can teach her new things and help her see things differently.

In addition, she has acknowledged that even adults continue to learn about life: their environments, themselves and those around them.

iv. Female children need to be protected from men

Kgomotso's childhood experience has led her to believe that female children are vulnerable and at risk of getting hurt.

In one of the sessions, Kgomotso graphically described the time when she was almost raped by her mother's boyfriend, and explained how her brother had woken up and come to her rescue.

In December 2006, after Kgomotso received a protection order against her husband, he broke into her house and destroyed all of her personal belongings. This frightened Kgomotso terribly and she decided to send her daughters to KwaZulu-Natal. Melusi



had never harmed her daughters in the past, but Kgomotso did not want to take the chance of this occurring. She described his behaviour as aggressive and abusive.

Kgomotso also mentioned another incident when Melusi was under the influence of alcohol and he began beating her. She said that he was so aggressive that she could not control him. During that incident, she began to fear for her life and the lives of her daughters. In order to protect them and herself, she started hitting Melusi with the heel of her shoe. She went on to say that the image that her daughters were left with was one of chaos and destruction. Melusi began to bleed profusely and Kgomotso believes that this was a very traumatic experience for her and her girls; she regrets that they had to witness this incident. She added that, not only does she need to protect them physically; she also needs to protect them from witnessing such aggressive behaviour.

v. Family members must take care of each other

This family rule was first introduced by Kgomotso's adoptive parental system, when her aunt searched for her and her siblings and applied for custody. When Kgomotso needed to find a place of safety for her daughters, she asked her aunt for help.

Despite her differences with her mother, Kgomotso has allowed her mother to stay with her. Kgomotso finds her new living arrangement quite stifling as she sees her mother as demanding and overbearing. However, she feels that her mother is family and she should, therefore, assist her.

vi. Privacy should be respected and should not be violated

When Kgomotso discovered that she was HIV-positive, she confronted her husband. Melusi was very angry and confrontational. He denied having sexual relations outside of their marriage and blamed her for introducing HIV into their relationship. He also refused to disclose his status to her.

Kgomotso stated that when she and Melusi would argue, there were many occasions when Melusi would bring up her HIV status and would insinuate that she was having an extramarital affair. This angered Kgomotso, as she did not want her children to find out about her status.

Kgomotso is thankful that her children did not pay attention to these accusations, and that they have not realized that she is HIV-positive. She has yet to disclose her status to them and in fact, has not told any one in her family.



vii. Support is important

Kgomotso has seen a dramatic change in Neo's behaviour since the intervention. She perceives her to be very loving and supportive towards her and her siblings. Kgomotso believes that Neo's caring nature has helped alleviate some of her stress. She is able to ask Neo for assistance around the house, and feels that her youngest daughter is learning from Neo's modelled behaviour.

In addition, Kgomotso revealed that her oldest daughter, Thuli, wrote her a letter when she separated from Melusi. In the letter, Thuli told her mother that she "must hang in there" and that she loves her very much, thus demonstrating her support for her mother.

Kgomotso has always felt that her aunt and uncle have been very supportive of her and her children.

Mrs Botha is an elderly white lady who has had Kgomotso in her employ for seven years. Kgomotso feels very close to Mrs Botha and she feels privileged that she has a supportive employer. Kgomotso has informed her employer of her status. Mrs Botha takes care of Kgomotso by purchasing multivitamins for her on a monthly basis and flu medication when she requires it. In addition, she has taken time to learn about HIV/AIDS and has shared her knowledge with Kgomotso.

Kgomotso made no mention of external support from her in-laws.

viii. Children are too young to understand what HIV/AIDS is

Kgomotso has not disclosed her status to her children as she believes that they are too young to understand the implications of this disease. She feels that if she does tell them, her children will be traumatised.

Her children are aware that she is on medication; however they do not know the reason for this. Kgomotso suffers from high blood pressure and believes that her children assume she is taking medication to regulate her condition.

5.3.5. Boundaries

In Kgomotso's family of origin, rigid boundaries were identified between the biological siblings and their biological parental system. The maternal siblings and the extended relative



system are disengaged from this system. With no support, and limited interaction from the biological parental system, there is restricted access between the subsystems.

The boundaries between the maternal sibling subsystem and the extended relative subsystem indicate a distinction from the above description of the biological parental system. Here, clear boundaries are applied and supportive behaviour is encouraged. The maternal sibling subsystem and the adoptive parental subsystem exchange information openly and frequently and everyone feels that they belong in the system.

As a couple, Melusi and Kgomotso also displayed rigid boundaries in their relationship. There was insufficient communication and support between the two. Furthermore, Melusi and Kgomotso were, and still are, uninvolved in each others affairs. Such rigid boundaries between the two often impacted negatively on their interactions with their children. For example, Kgomotso described how Melusi would often spark Neo's jealous outbursts and encourage her to be demanding. Kgomotso described an incident where she bought her oldest daughter, Thuli, new clothes and Melusi suggested to Neo that Kgomotso did not love her as she did not get anything. The next day, Melusi took Neo shopping and bought her several gifts in order to show his love for her. When they returned home, Melusi did not give Thuli anything and said it was because she was not his child.

Prior to the intervention, Kgomotso believed that she had instituted clear boundaries between her and her children; however, there was an element of rigidity at times which seemed to confuse her children. The message she was sending to her children was: "You can approach me, but do not approach me."

After attending the intervention, Kgomotso started to set clearer boundaries between her and her children. She described how support and open communication are now vital elements in their system. She adds that her children have been able to adapt to their new environment because she has explained to them the reason why they have been placed in their great aunt's care. She also keeps in contact with them on a weekly basis and visits them in KwaZulu-Natal as often as she can. In addition, she constantly tells them that they will be able to return home once she has saved up enough money to move.

5.3.6. Power, alignments and coalitions

In Kgomotso's family of origin, her mother tended to hold most of the power in the system. In the past, the members of the sibling system "lost their voice" to their mother. They were



raised to obey her and not to talk back to her. It is interesting to note that even now, as an adult, Kgomotso still becomes a "child" around her mother. Kgomotso has learnt to be assertive in all her relationships but when it comes to interacting with her mother, she is not able to assert herself.

In this system, the biological mother is not liked by the other members of the family. They have ostracized her and have very little to do with her. Kgomotso has allowed her to stay in her house, and to utilize her resources, but their relationship is like that between a boarder, or tenant, and landlord, only the mother does not pay rent or contribute to anything around the house.

In Kgomotso's nuclear family, a power struggle is evident within the couple subsystem. In the past, Melusi would exert his power over Kgomotso by physically beating her or demanding sex from her when he was intoxicated. Kgomotso would always fight back physically. She has recently displayed her power over him by getting a restraining order and serving him with divorce papers. However, this did not give her the result that she had hoped for, as Melusi later broke into the house and destroyed her personal belongings and her work. He also stole her identity document and her passport, as well as those of their children. This has set her back financially as she has had to personally incur the costs of her client's wedding dress and she has also had to apply for new identity documents and passports. This ongoing power struggle has now resulted in Kgomotso prohibiting Melusi from seeing their children.

Prior to the intervention, Melusi and Neo were aligned and had formed a coalition against Kgomotso's oldest daughter, Thuli. The two of them would make her feel very unwelcome in the home and Kgomotso felt guilty about the way they treated her child. A lot of pressure would be placed on Kgomotso so that her daughters would not feel that they needed to compete for her love and attention.

5.3.7. Circular patterns of interaction

When Kgomotso was pregnant with her youngest child, she was diagnosed with HIV. At the time, she was convinced that being HIV-positive meant that she was going to die instantaneously. This belief created tremendous stress and her blood pressure escalated. Eventually her blood pressure became so high that she was at risk of either losing her unborn child or dying and was hospitalised immediately. This event reinforced her belief that she was dying.



Kgomotso says that she started to neglect her children at this time. Not only was she not at home for a long periods of time, but when her children came to visit she distanced herself from them emotionally, as she felt that she had let them down as a mother. Kgomotso felt that the last thing that she could do to protect her children as a mother, was to shield them from not coping with her death when she passed away. Thus, she felt that by distancing herself emotionally from them would aid in her favour i.e. they would perceive her in a negative light and would not want to mourn for her when she passed away. The more Kgomotso withdrew from her children, the more her children came to visit her and yearn for her attention. The knowledge that her children had made the effort to walk a considerable distance from school to the hospital every day to see her, pleased Kgomotso, and she began to get better.

During the intervention, Kgomotso learned various relaxation techniques that she has incorporated into her lifestyle. The more time she spends dealing with her stress the more she feels in control of her life and health and the less frustrated she feels. Consequently, she is better able to relate to her children more warmly and they in turn feel that she is more approachable. This process facilitates an open, supportive environment whereby both subsystems are able to communicate openly towards each other. They now spend time together as a family and engage in various activities, such as playing together. The more time they spend together, the closer they become.

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In the past, when Kgomotso felt frustrated, she was less likely to listen to her children. The more they misbehaved, the less tolerant she became, resulting in her beating her children. She elaborated further by saying that, the more she beat them, the less they would listen to her and the more they would misbehave, and thus, this interaction cycle would escalate.

Kgomotso believes that the intervention has had a positive influence on her and on Neo. She feels that they have both learnt various skills and new information that they have



introduced into their family which have assisted them in making the relevant changes, for example, identifying emotions, problem-solving, discipline methods, coping skills, life skills, communications and listening skills. However, having said this, Kgomotso still does not feel safe enough to disclose her status to her children or to her other family subsystems. She is fearful that she will be judged by her children and her extended family as being promiscuous and for being responsible for breaking up her marriage; as a result she will be ostracized. The longer Kgomotso holds on to her secret, the safer she feels in the system, as the rest of her family is not aware of her condition.

As mentioned earlier, prior to the intervention, Neo was jealous of her older sister which made her sister feel unwelcome. Thuli's silence, in turn, encouraged Neo to continue this behaviour. Consequently Kgomotso felt torn between the two girls and began to overt her attention to both.

Kgomotso stated that after the intervention Neo began to let go of these emotions and beliefs and became more supportive of her sisters and mother. Kgomotso explained that the more supportive Neo is, the more interaction there is in the family and tension is thus reduced. Thuli feels more welcome and has developed a sense of belonging; she now wants to engage more with the other members in the family. Kgomotso does not feel that she has to work as hard as she used to, to assure her daughters of her love for them. For example, she is now able to purchase things for both Thuli and Neo without having to think about how the other child will react.

Another important circular pattern that is identified in this family is that of the couple. It is not apparent from the case-study what it is that causes Melusi to act aggressively towards Kgomotso. Kgomotso believes that Melusi's alcohol consumption sparks his aggressive behaviour. What is apparent though, is that the more Melusi abuses Kgomotso the more Kgomotso retaliates. This aggravates his aggression and abusive behaviour, thus intensifying the circular interaction.

Kgomotso's relationship with her husband is in sharp contrast to her relationship with her mother. The more autocratic and aggressive Kgomotso's mother is, the more submissive Kgomotso becomes.

5.3.8. Evaluating the impact of the intervention on the system in terms of feedback, homeostasis and change



Since the intervention, Kgomotso and her family have experienced significant changes. Kgomotso attributes many of these changes to her participation in the intervention.

Firstly, Kgomotso noticed a change in the way that she perceives her life. Prior to the intervention, she grappled with the idea of being HIV-positive. She associated HIV with a death sentence and worried about what would happen to her children if she became ill or died. Once she began to attend the intervention, she started to expand her understanding of HIV/AIDS. She now perceives herself to be more confident and has a greater will to live. Prior to the intervention, Kgomotso allowed herself to surrender to her negative thoughts. She described how her thoughts consumed her, as she spent most of her time thinking about how HIV was destroying her life. After the intervention, she took control of her thoughts when she realised that she could still live a healthy life for a long period of time. This new outlook on life has freed her from the heaviness that she carried with her in the past. Kgomotso summed this up by saying: "I live freely; I am not scared or afraid. I don't think a lot about HIV - I live my life normally but carefully. I know that I must take care of myself – I need to take vitamins and I am doing that and I thank God that up until today I am still alive... that I am still strong".

Subsequent to the intervention Kgomotso also felt empowered to disclose her status to her employer, who in turn responded in a positive and supportive manner.

Kgomotso said that she has also learned how to identify when she is feeling stressed and is now more equipped to manage her stress. For example, she dedicates fifteen minutes a day to herself and often engages in a guided fantasy or spends time gardening.

Kgomotso acknowledges that before she attended the intervention she was: "...in the dark and not knowing how to handle the children." She believes that the intervention has empowered her with knowledge that she has been able to apply to her child-rearing practices. For example, she has changed the manner in which she disciplines her children. In the past, she wasn't willing to hear their explanations and the family never discussed alternative ways of handling a situation. Kgomotso would merely reprimand her children and "beat them" as she felt that this was the way to deal with their misbehaviour.

Kgomotso explained, "The most important thing that I have learnt about the children is that if you are always wild with them, you don't get a chance with them – if you always hitting them and always shouting at them, the children become ignorant with you (they do not respect you and ignore you). They don't hear; they don't listen to what you are telling them, instead they

become apart from you. I learned that I must listen to them and work (communicate) with them. It makes things a lot easier because they understand me and I understand them."

She added that she has changed her manner of interacting with all her children and not only with Neo, who attended the children's intervention. However, Kgomotso points out that Neo modelled behaviour to her siblings, such as sharing her emotions, showing support and assisting with household chores. Kgomotso believes that there has been a definite change in Neo's behaviour and in the manner that she interacts with the other members of her family.

The family system also underwent various structural changes: Kgomotso and Melusi separated and the children moved to KwaZulu-Natal where they are now living with their great-aunt and great-uncle. Kgomotso's mother has moved in with Kgomotso. Even though these structural changes are not directly linked to the intervention, the intervention did play a role in these changes, as it helped Kgomotso develop problem-solving skills and taught her to be more self-accepting and assertive, all of which have contributed to her making the decision to separate from her husband.

Kgomotso has described a change in the family members' alliances. Before the intervention, Neo was closer to her father than she was to her mother and Thuli, and during this period of time Thuli did not feel that she belonged in the family. After the intervention, however, Thuli stopped feeling this way and became closer to Kgomotso and Neo. Furthermore, Kgomotso perceives another dynamic change, in that she believes that her daughters have aligned themselves with her and have ostracized Melusi, effectively forming a coalition against him, as they now perceive him to be the cause of the instability in the family.

Kgomotso added that after the intervention and before her children moved to KwaZulu-Natal she spent more time with her children than she did before. They spent time joking with each other and playing games, such as cards and Marabaraba². They also spent time talking about various topics, attending church, reading stories to each other and doing homework together.

Kgomotso tries to give her daughters as much stability as possible by visiting them as often as she can. During her visits, she tries to incorporate as many of the abovementioned family

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² An African board game



activities as she can. Kgomotso feels closer to and more comfortable with her children since the intervention, and believes that they feel the same way about her.

Even though so many changes have taken place in this system, certain aspects have not changed. For example, Kgomotso is still not able to stand up to her mother and still feels like a "voiceless" child around her. Her mother also disagrees with the new way in which she is choosing to discipline her children as she believes that Kgomotso is spoiling her children. Kgomotso still believes that she cannot disclose her status to her children as she feels they are not old enough to understand the implications of HIV/AIDS.

5.3.9. The impact of HIV on the family system

HIV played a destructive role in Kgomotso's marriage as distrust and disloyalty were introduced into her relationship. When Kgomotso was diagnosed with HIV, Melusi blamed her for introducing HIV into their marriage and Kgomotso resented him for his accusations and infidelity. She feared that her children would hear his accusations and would believe his lies.

Before the intervention, Kgomotso allowed HIV to distance her from her children emotionally as a means of punishing herself for letting her children down. Her belief that she was going to die and leave her children orphaned, angered her as she internalised this as abandonment.

HIV also instigated the use of secrets between the parental subsystem and the children subsystem as a means of protecting the children, as they were viewed as being too young to understand the implications of HIV. Even after participating in the intervention, Kgomotso remains very secretive; she sees secrets as a means of safeguarding her position in the family and a way of protecting the family system from further disruption and unsettlement.

The children are unaware of the presence of HIV in the family and thus HIV does not influence their perceptions of their parents and their circumstances.

5.3.10. Reflections from the observing system

At all times Kgomotso presents herself as a friendly, happy and optimistic individual. As a facilitator and researcher the author experienced her to be candid. The way Kgomotso



portrays her story illustrates her hardships that she has endured as well as the way she has managed to survive her ordeals.

Kgomotso proved to be a role model in the mother's group whereby she encouraged the other women to try and become self-employed and self-reliant. She also assisted some of the mothers outside of the intervention by teaching them how to sew.

Her personal strength, which surfaced in the session, also illustrated to the other members that they should voice their opinions and not accept blame from a man purely because they are seen as the 'weaker' gender.

As a woman the facilitator/researcher often found that she sympathized with, and aligned herself, with Kgomotso. She often reminded herself that Melusi was not present to give his version of the story, and that she should "align with everyone and no one at the same time" and offer a "non-judgemental view".

Towards the end of the intervention, Kgomotso was not able to attend some of the combined sessions due to work obligations. However, she would still send Neo to the sessions and would catch up on what she had missed by allowing Neo to teach her in their private time. This illustrated that Kgomotso and her family were able to make the relevant changes by merely being nudged (perturbed) by an external system i.e. the intervention.

During the research process it was rewarding for the facilitator to hear about the various changes that Kgomotso and her family had undergone. It was particularly interesting to hear how two members of a system were able to introduce new information to the other members in the system, thereby encouraging the system to shift drastically.

5.4. CASE STUDY THREE – Andile

5.4.1. Background information

Andile, aged 31, originates from the Northern Cape and lives in Atteridgeville with her husband, children and her younger brother. Currently Andile has three children as one child, a twin, passed away shortly after her birth, due to HIV. Even though Andile is mourning the loss of her daughter, she is relieved that her surviving twin daughter and her sons are not HIV-positive.



Andile has married into the Muslim faith and her husband, Enoch, is the father of her two surviving children and deceased child. At the time of the interview, Andile stated that she and Enoch were constantly arguing because he wanted to take a second wife. Even though Andile is accustomed to this tradition, she was not pleased with her husband's motives for his decision.

Andile's husband has admitted that he is already involved with another woman and will continue to see her if she does not consent to the marriage. Andile explained that she feels pressured to allow her husband to take a second wife; she is concerned that they will continue to argue if she does not give her consent.

5.4.2. The system's components

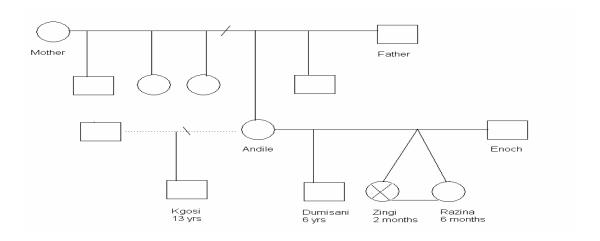


Figure 5: Andile's genogram

In Andile's family of origin, she is the fourth of five siblings, two of which are male and three are female. Her mother still lives in the Northern Cape and she does not know the whereabouts of her father, who left home in 1986.

Andile has a thirteen-year-old son (Kgosi) from a previous relationship. Enoch is the father of Andile's six year old son, Dumisani, and twin daughter's Razina, who is eight months old, and Zingi who is deceased. Up until 2006, Andile's oldest son was living with his maternal grandmother in the Northern Cape. He now lives with his mother and extended family. Andile's younger brother also lives with them as he works with Enoch in Pretoria.

The above family description indicates that there are various subsystems within Andile's family. In her family of origin, her mother and absent father make up the parental subsystem



and Andile and her siblings make up the sibling subsystem. In addition, Andile and Enoch make up the couple subsystem and her children make up the sibling subsystem. For the purposes of this case study, they will be referred to respectively as the grandparent subsystem, the maternal-sibling subsystem, the parental subsystem and the sibling subsystem (or grandchild subsystem).

5.4.3. Relationship styles

Andile and Enoch seem to have a parallel relationship which means that they alternate between complementary and symmetrical relationship styles. For example, her husband is dominant and she is submissive when it comes to the issue of taking a second wife. Andile illustrated this when she said that her "husband will not change...I do not want to fight...solving the problem between me and my husband is that I must keep quiet". However, when a decision had to be made about whether to allow her brother and son to live with them in the house, there was equality in the decision-making process: "We talked and talked," said Andile. It was not always like this; Andile said that, in the past, the couple would "shout and say bad words to each other".

Before the intervention, Andile and Dumisani seemed to have a complementary relationship wherein Dumisani would manipulate Andile and she would feel as though her voice had been taken away from her by him. For example, when they would go shopping and he would request something she could not reason with him. He would scream and cry, to the point where his mother would feel embarrassed and succumb to his demands.

After the intervention, Andile began to perceive their relationship differently. She learnt to explain herself in a way that Dumisani understands and he no longer demands things. In addition, he is able to do the same with her. This illustrates a shift from a complementary relationship style towards a symmetrical relationship.

It was not evident from the interview which relationship styles are practised in Andile's family of origin.

5.4.4. Family rules

A few family rules were identified, depicting the manner in which Andile's family function.

i. In the past disciplining meant giving a beating now it means talking and explaining



Andile stated that, prior to the intervention, she would beat her children and "corrupt" (manipulate) them to do what she wanted them to do, because she believed that she knew better than they did. She has now learnt how to listen to her children and discuss with them their wrongful behaviour when they do something wrong or are disobedient.

ii. Open communication is important

Andile and Enoch believe that communication is important and they normally discuss their problems in the privacy of their bedroom. They also encourage open communication amongst their children even though they do not discuss their own difficulties with them.

iii. <u>Tiptoeing around problems to protect the feelings of others</u>

In spite of the above mentioned rule, Andile avoids speaking to Enoch about his decision to take on a second wife as she does not want to upset him.

In this family, it is the children's task to remind Andile to take her antiretroviral medication. She has not, however, told them the reason why she takes these tablets.

It is unclear from the information obtained whether Andile was HIV-positive prior to or after her marriage to Enoch. Enoch knows Andile's HIV status and he supports her and encourages her to seek medical attention. Enoch, however, does not want to be tested. The couple is not able to discuss this issue without Enoch becoming angry and upset, which consequently discourages Andile from speaking to him about his physical well-being.

Even though Andile disclosed her status to her younger brother in 2001, they have not discussed her illness since. Andile feels that he may have forgotten about it as he was only twenty-one years old at the time. She also says that her brother is very shy and this may be another reason why he does not ask her questions about her well-being. Andile has not told any of her other siblings about her status as she does not want to upset them; she is also concerned that they will react negatively towards her once they find out that she is HIV-positive.

iv. Children must love and respect their mother because she is their mother

Andile believes that her children will always be true to her for the simple reason that she is their mother.



v. Family members must take care of each other

Andile's brother lives with them because he has nowhere else to stay.

Enoch has accepted Andile's oldest son into his home and treats him as his own child.

The thirteen-year-old looks up to Enoch, and shows him respect.

In addition, Andile and Enoch have taught their children to look out for each other at school and at home.

vi. Privacy should be respected and should not be violated

Even though Andile's brother, mother and husband know about her status they have not discussed this with the other members in the maternal-sibling subsystem and sibling subsystem. Nor have they spoken about this outside of the family with other interacting systems. They have respected Andile's decision to keep her disease private and have allowed her to disclose to those she feels closest to, for example her best friend, medical staff, and the mothers and staff involved in the intervention.

Furthermore, Enoch refuses to be tested as he does not want to know his status. Even though Andile is concerned about her husband's physical well-being she has chosen to respect his decision, though it has been difficult for her to accept.

vii. Children and rural people are not able to understand what HIV/AIDS is

Andile has not disclosed her status to her children, as she believes that they are not old enough to understand what HIV is. Even though they know that she is on medication, she has not told them the reason for this.

On the other hand, she has disclosed her status to her mother but feels that her mother does not understand the effects of HIV. When Andile was pregnant, her mother believed that Andile was going to die and leave her children behind.

Andile also mentioned that her experience with rural people has been that they have a limited knowledge of HIV. Their perception of an HIV-infected person is negative and they believe that a person with HIV will die within a year of being diagnosed.

5.4.5. Boundaries

Since Andile started attending the intervention, the family has implemented clear boundaries between the parental subsystem and the sibling subsystem unlike before where rigid boundaries were executed. The parental subsystem is firm, for example they have set



certain rules for disciplining, and they are also flexible, in that they spend time listening to their children. This encourages the sibling subsystem to interact openly with the couple and creates a sense of belonging. Whereas before the intervention, no rules were set and discipline was a means of relieving the frustration that was experienced by the parental system. Andile also mentioned that, prior to the intervention, she and Enoch would not spend a lot of time interacting with their children.

In addition, the unwritten family rules control what type of information can leave the parental subsystem; for example, the issue of the second wife and who should know and not know about Andile's HIV status.

Proximity seems to also play a role with regards to how permeable the family's boundaries are. For example, the family members that live in Andile and Enoch's home seem to interact frequently; however, those living outside of the home do not have much contact with these family members.

Prior to the intervention, Andile interacted with another system (her friend), when she had a personal problem instead of speaking to her husband and to the members of the grandparent and maternal-sibling subsystem. She stated that she does not have much support and that it is not easy for her to speak to her family about personal problems, especially where her status is concerned. Though her husband had always supported her, Andile found it easier to talk to her friend. Unfortunately, Andile has not been able to get in touch with her friend for the past year and no one knows her whereabouts. Happily, Andile has managed to make new friends through the intervention whom she visits and interacts with on a regular basis.

From this description, it appears that there are rigid boundaries between the members of the parental subsystem and the members of the grandparent and maternal-sibling subsystem, making it difficult for Andile to obtain the support that she needs. Defining this as a problem, Andile has tried to address this problem by introducing her nuclear family to new information from external systems, (i.e. information that she obtained from the intervention and from the other mothers who attended the intervention) allowing the system to become more open than before.

5.4.6. Power, alignments and coalitions

In Andile's family of origin, her father holds a great deal of power even though he is not present. The family members have tried several times to locate him but have not succeeded.



When Andile was a child, her mother had to work full-time and would often leave her children at home alone. In her absence, Andile's oldest brother would dominate the rest of the siblings. This would cause the rest of the siblings to align together and form coalitions against him, as they did not like the way in which they were being treated. Furthermore, Andile felt that, growing up, she was the closest to her mother in the family.

Prior to the intervention, Andile felt that her relationship with her mother was stronger than all her other relationships. In her nuclear family, she perceived her children to be closer to her husband. She stated that once she started to interact differently with her children, they became closer to her, and withdrew slightly from their father. In addition, Andile's oldest son is closer to his grandmother than the rest of the grandchildren are, as he lived with her for 12 years.

Before the intervention, Andile's second son displayed power in his relationship with her. His outbursts in shopping malls would cause Andile to give in to his demands. Andile's parental voice was often taken away by her embarrassment. When Andile adopted more effective disciplinary and child rearing-methods, which she learned at the intervention, she was able to exert power over her son.

Andile added that Enoch has been supportive in the past and even though his decision to take a second wife has put a strain on their marriage, she still believes that he will be supportive of her in the future. It is apparent from this scenario that Andile and Enoch share power in the family but, at times, Enoch has a greater influence on the decision-making process and on activity outcomes. The following examples clearly depict this: Enoch's behaviour has influenced Andile to consent to the second wife and not wanting to be tested influences the way Andile interacts with him, concerning his physical well-being.

It is not evident from the information obtained whether there are coalitions in the nuclear family and family of origin.

5.4.7. Circular patterns of interaction

Prior to the intervention Andile indicated that the more she believed she was going to die from the HIV infection, the further away she distanced herself from her children emotionally (in order to safeguard them from mourning for her when she passed away) and the closer her children became to their father. In return, the closer they were to the father, the less needed she felt. From this interaction, she also experienced greater difficulty in disciplining



her children and perceived them to be resistant when she spoke to them. Consequently, the more resistant they were, the more frustrated she became - indicating a circular reaction.

Andile also admitted that, in the past, after arguing with her husband, she would often act as though something was wrong so that she could get her husband to change his mind and agree with her. However, the more she would act as though something was wrong, the more Enoch would ignore her, and the angrier she would become. In return, the angrier she would be, the more she would act as though something was wrong and often vent her anger towards her children. After much time she realized that her reaction would merely confuse her children; they did not understand what was happening and they distanced themselves from her, as they did not know how to communicate with her.

After spending time interacting with the other mothers involved in the intervention, Andile believes that she must not let her children know what is going on in her marriage. Thus, she has now adopted a new approach: when she and her husband have a difference of opinion, Andile feels that it is better to keep quiet and not argue. The more she keeps quiet, the more her husband does what he wants. Even though Andile is not happy with Enoch's decisions, she believes that it is better because "the outcome is the same in the end and it saves [her] from wasting time and energy arguing". In addition, she believes that her children do not realize that there is a problem between her and their father.

5.4.8. Evaluating the impact of the intervention on the system in terms of feedback, homeostasis and change

Andile points out that the intervention has had a positive influence on her life and on Dumisani's life. She has noticed various changes that have taken place on a personal level (for example, she feels more positive and has found a reason to live), as well as within her family. Furthermore, Enoch and her sons have mentioned that they have noticed these changes too.

Andile attributes these changes to what she and her son have introduced into their system and subsystems. For example, she said that she has learnt how to take care of her children, how to discipline them, how to play with them and how to listen carefully to how they are feeling. She also believes that her son learnt the same lessons after attending the children's intervention.



In addition, she expressed that she has learnt how to utilize and adapt these skills where her other children and her husband are concerned. She and Enoch now discuss things, unlike before, where they would often shout at each other.

Since this change took place, Andile feels more content in her relationships with her children. She also perceives her children to be closer to her now and states that, by altering her disciplinary methods, Dumisani's responses have also changed and he has become a role model for Kgosi and his sister.

Andile also points out that there are certain areas that did not change after the intervention. For example, she and her husband still argue over his personal beliefs i.e. not wanting to be tested. It is clear that in order for the system to maintain its homeostasis, the couple rely on these beliefs to set the arguments in motion. If they were to agree on these beliefs, then the couple would have to change the family rule: "Privacy must be respected and not violated".

In addition, Andile reveals her ambivalence towards her siblings, as she would like them to know about her status, but, at the same time, she would rather they did not know. She has placed herself in a double bind: she trusts them, but does not trust them. It is clear that Andile is not ready to make this change in her life, as she is still fearful of the outcome. Her fear of rejection here acts as the homeostatic agent which inhibits the possibility of change in her relationships with her siblings.

Overall, Andile feels more optimistic about her life now, than she did before the intervention, when she "thought there was no hope". She is content with the change that has taken place at this stage.

5.4.9. The impact of HIV on the family system

Initially, HIV immobilised Andile from living her life free of fear. She was so terrified, that she pushed her children away from her in order to protect them. She believed that if she was not part of their lives, they would not mourn her or feel saddened by her death. However, HIV brought her closer to her husband, who has continued to support her and does not treat her any differently. Although Enoch is supportive of Andile, he is against the use of precautionary measures during intimacy and insists that the "pulling out method" is sufficient for safe sex practice as opposed to using a condom.



HIV seems to be present yet absent in this family system, in that, those that know about its presence do not talk about it, for example, Andile's mother and younger brother. Furthermore, the couple is not allowing HIV to come between them or determine their identity and future plans. For example, when their baby daughter passed away, they mourned her loss without disclosing the cause of her death to the family members. In addition, Enoch still wants a second wife, regardless of what his status might be. He is not concerned about how his status might impact on his relationship with his wife and future wife.

The children have not been informed of the presence of HIV in the family, and thus, HIV is not able to influence their perceptions of their parents and their circumstances.

5.4.10. Reflections from the observing system

As a facilitator observing during the intervention, the author viewed Andile as being cooperative, diligent and eager to learn. She always arrived twenty minutes before the session and brought her baby *and her son* with her. Andile was keen to share her stories with the other mothers and was always open to new information.

Initially, in the combined mother-and-child sessions, Andile struggled to interact with her son. She seemed unable to keep her son's attention during a task. For example, she would allow him to wander off while she continued with the task on her own. She was determined, however, to gain his trust and bridge the distance between them which she managed to do once she became comfortable with playing.

Andile's creativity came to the fore when she modified the tasks so that her baby daughter could be included in the activities. By doing this, her son interacted with his sister as well, and he was able to convey his caring nature towards his mother and his younger sibling.

Over the 25 sessions, Andile evidenced great personal growth, for example, she became more insightful both intrapersonally and interpersonally. She continued to work on her shortcomings and relationships with her family outside of the intervention, and viewed this challenge as a personal project.

It was interesting to note how a change in Andile's system began to unfold and shift, as no specific change could be predetermined by the author in either the role of facilitator or that of researcher during and after the intervention.



Andile's story challenged the researcher's views of marriage. Being a newlywed, and coming from a culture where polygamous marriages are not the norm, the researcher was left wondering how Andile will allow Enoch to take a second wife. Furthermore, in the context of HIV, the researcher wonders how this second marriage, and extension of the couple system, will exacerbate infections and re-infections within the couple system, since the couple does engage in unprotected sex.

The author was, at all times, aware of her prejudice and refrained from asking these questions during the research process as these questions would have diverted the conversation away from the research question and leave Andile feeling judged.

5.5. CASE STUDY FOUR - Thandi

5.5.1. Background information

Thandi is a 33-year-old woman who lives in Atteridgeville with her maternal grandmother and her mother's siblings. She has never been married and has an 11-year-old son, Bongani, from a previous relationship who also lives with her. She is currently pregnant with her boyfriend's child.

Thandi has been living with HIV since 2003. Her boyfriend, Elias, is also HIV-positive. They are both aware of each other's status and are supportive of one another.

Thandi has been working at a crèche for the past ten months and is fulfilled by her work.

5.5.2. The system's components

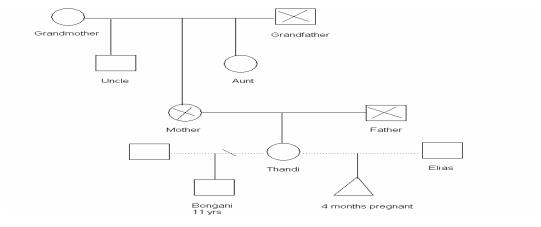


Figure 6: Thandi's genogram



Thandi is an only child and stays with her maternal grandmother. Both her parents and her maternal grandfather are deceased. Even though Thandi is not close to her aunt and uncle, she regards them as being her siblings.

From a systemic perspective, the parental subsystem is absent in Thandi's nuclear family and has been replaced by her maternal grandmother. For the purposes of this paper, this system will be referred to as the grandparent subsystem. Thandi and Elias make up the couple subsystem. It is important to note that Thandi is also part of the grandchild subsystem and her maternal relatives make up the maternal-sibling subsystem. Bongani and his unborn sibling make up the sibling subsystem and great-grandchild subsystem.

5.5.3. Relationship style

Thandi's relationships with her grandmother and son, as well as her relationship with her boyfriend, are symmetrical in style. She believes that there is equality in her relationships and that no one member is more influential than the other. Everyone has the opportunity to be heard, including her son who is the youngest in the family.

5.5.4. Family rules

A few family rules were identified, depicting the manner in which Thandi's family function.

i. Respect is important.

The family members see respect as being the foundation of their relationships. They believe that one should first learn to respect oneself before one is able to respect others. Thandi said: "If you are not able to respect yourself, how will other people be able to respect you?" It is therefore important to let others know when one is feeling disrespected. For example, Bongani told his mother: "You must not use vulgar language when speaking to me because if I use it towards you, you will not like it…so if you want me to respect you, you need to show me respect as well".

ii. Support means love and respect.

When Thandi first found out that she was pregnant with her second child, she considered having an abortion, as she felt that Elias was not supportive of her, and she questioned his involvement with her child in the future. Later, Thandi discovered that an abortion could endanger her life, as her CD4 count could drop drastically during the procedure. After she shared what she had learnt with her partner, Thandi appreciated

the fact that Elias told her that she should not go through with the abortion and that he would be there for her. She feels that he is supportive as he does not want to lose her and respects her decision to keep the baby. In addition, Elias and Thandi are both HIV-positive and they love and respect each other unconditionally despite their status and previous history.

Thandi also mentions that the family member who is least supportive of her is her uncle because he does not show her that he cares about her.

iii. Open communication is important.

Thandi's grandmother has raised her to voice her opinion and to speak up when something is bothering her. It is for this reason that Thandi perceives that she has an open relationship with her grandmother and has created the same type of relationship with her son. She also encourages her son to interact in the same manner with the other members of the family.

iv. Family members take care of each other.

This rule is depicted in the following examples:

- When Thandi's parents passed away she went to live with her grandmother.
- After Thandi fell pregnant with Bongani, her grandmother did not judge her and offered to take care of her. Furthermore, when Thandi is ill, her grandmother tends to her and gets her the medical attention that she requires. In return, Thandi does the same when her grandmother is not well.
- Even though Bongani is not aware of his mother's HIV status, he has made it his duty to remind her to take her medication.
- The family members' relationship with the uncle is strained; however, they still acknowledge his presence in the family.

v. Children are too young to understand what HIV is.

Thandi has disclosed her status to everyone in her family except Bongani. She feels that he is too young to understand the implications of HIV and does not want to cause him any distress.

Furthermore, she is unwilling to engage in a discussion about HIV and AIDS with Bongani. Although Bongani is learning about HIV at school and from watching television, he has not managed to grasp certain concepts concerning the virus and his mother chooses not to address these misconceptions. For example, she once asked



him to scratch her lower back and he told her that he couldn't touch other people's bodies because that was how HIV was transmitted.

5.5.5. Boundaries

From Thandi's description of her family, it is apparent that there are clear boundaries within her family system. She indicates that her grandmother has created a warm and loving environment for her and Bongani. Thandi and Bongani have been encouraged to be independent. For example, Everyone in the family contributes to various house hold activities including Bongani who has been given chores to do around the house. Just like everyone else in the family he does them in his own time. When Thandi reminds him to do the chores, he tells his mother that he will do them and does not need her to nag him. Thandi realizes that she sometimes feels impatient with her son because she likes things to be done immediately. Thandi described how everyone in the family feels that they belong in their home and they know that they can depend on each other in times of crisis.

According to Thandi, she and Elias display clear boundaries in their relationship as they are encouraging and supportive towards one another. They are seen as a couple but they have not lost their individual identities. In other words, Thandi and Elias respect one another's opinions and discuss things openly without the fear of being judged. For example, when Thandi was thinking of terminating her pregnancy, Elias did not stop her from investigating the matter. He offered her his support and told her that he would stand by her no matter what her decision.

The family system can be characterised as negentropic, as there is a balance between the openness and closedness of the information that enters and leaves the system. This is also apparent in the external working systems that Thandi engages in. For example, Thandi considers her employer to be very supportive and encouraging; she also feels that she can speak to her employer about issues such as HIV without having to explain her interest in the topic. Furthermore, she is able to discuss her difficulties, such as not getting along with a parent, at the crèche, who she feels judged by. It is apparent that Thandi has an open relationship with her employer and co-workers where she feels comfortable to discuss various issues with them. However, she has not disclosed her status to them, as she fears they will not trust her with the children she supervises, ultimately ostracising her and dismissing her from her job.



In addition, Thandi describes the boundaries between her uncle and the rest of the family as rigid. Her uncle is not involved in the family affairs and does not support the other members of the family.

5.5.6. Power, alignments and coalitions

Thandi's grandmother holds most of the power in the family as she is the decision-maker and primary breadwinner in the home. Up until Thandi found work, the family relied on the grandmother for financial assistance. Thandi constantly seeks approval from her grandmother and tries not to disappoint her. She has modelled this behaviour for Bongani who also tries his best to please his grandmother.

Thandi is closest to her grandmother, and her son, and the three of them spend most of their time together. Thandi's aunt seems to be the mediator between this alignment and the uncle. The uncle does not get along with the other members of the family as he does not contribute to the family in any way. He is a present, yet absent, member in the system and his inconsistent behaviour confuses and frustrates the other members as they feel used by him. Thandi's aunt tries to keep the peace in the system, and even though she agrees with the other members, she feels obligated to assist her brother because he has nowhere else to turn. This often leaves her feeling unappreciated. However Thandi, Bongani and her mother do not feel sorry for her as they have warned her about his behaviour.

Thandi does not speak much about her boyfriend which left the researcher wondering about their relationship. When questioned about the relationship, Thandi mentioned that she does not see her boyfriend as part of her family as they are not yet married. However, they are very close and he is very supportive of her when it comes to issues that arise outside of the family system.

5.5.7. Circular patterns of interactions

At the beginning of the intervention, Thandi presented with hostile and aggressive behaviour which she attributed to the anger she felt about her HIV-positive status and to the fact that she was unemployed. She was impatient with Bongani's laid-back approach which prompted her to swear at him and shout at him. The more she swore at him, the more reluctant he was to listen to her and he continued to do things at his leisure. This would anger Thandi further, thus perpetuating a circular reaction.



One of the things that she learnt at the intervention was to spend time playing with her son. She has found that the more they play, the more they learn about each other's likes and dislikes. As a result, they've learnt to communicate more openly and honestly with each other without becoming angry. They have also learnt to respect each other and work closely with one another, thus strengthening their relationship.

Thandi has also become more accepting of herself. In order to alleviate her stress, she spends more time laughing at jokes and having fun with those around her. The more accepting she is of herself, and the less stressed and angry she feels, the more assertive she becomes. The less defensive she is, the more she is able to give of herself to others, and the more others, (her son in particular), want to spend time with her.

5.5.8. Evaluating the impact of the intervention on the system in terms of feedback, homeostasis and change

At the start of the interview, Thandi could only identify the changes that had taken place that affect her directly, for example: she found employment; became more self-accepting and felt empowered and optimistic about her status. The use of circular questioning encouraged her to gain a deeper understanding of the changes that had taken place in her relationship with Bongani.

Thandi had always believed that she had a close relationship with her son. As the interview progressed, she realised that the relationship had, in fact, been strengthened since the intervention. She realised that before the intervention, she and her grandmother would spend time talking to Bongani about various topics and they would often battle to get him to listen to them. Through playing (a technique that Thandi and Bongani had learnt in the intervention), Thandi taught Bongani an array of meaningful life skills that have assisted her in getting him to co-operate more with her and her grandmother.

Since the intervention, Bongani has managed to teach his mother how he would like to be treated. She has learnt to stop swearing at him and treats him with respect. Bongani is now able to communicate his emotions more openly and he is able to voice his needs more clearly during day-to-day activities with his mother. Thandi stated that her grandmother has also noticed these changes in Bongani.

Despite feeling closer to Bongani Thandi is still reluctant to disclose her status to him, as she is concerned that he will not understand the true meaning of HIV and that he will be



traumatised. In addition she is aware of the stigma surrounding HIV and wishes to protect him from being negatively affected. Consequently, not disclosing to Bongani, makes Thandi feel more secure in her relationship with him thus the status quo of the system is maintained. Thandi feels that the intervention has indirectly reinforced her decision to keep her unborn child. She has always wanted a second child, and now believes that by opting for a healthier lifestyle and living with an optimistic outlook she'll be able to carry her child to term. However, Thandi's pregnancy has threatened the subsystems that she belongs to i.e. the family subsystem and the couple subsystem. According to Thandi, Bongani feels threatened by the unborn baby at times. He is concerned that the baby will take up more of Thandi's time and resources and that there will not be enough money for both him and the new baby. The pregnancy is challenging Bongani's understanding of the family rules: "Family members look after each other" and "Support means love and respect". This upsets Thandi as she does not want Bongani to react in this manner.

In addition, the pregnancy had previously placed a financial and emotional strain on the couple system. Once Thandi and Elias worked through these difficulties and made the decision to continue with the pregnancy, the couple managed to adjust to their new circumstances and maintain the stability of their relationship. However, even though Thandi perceives Elias to be more supportive of her and of the baby now she is still concerned about how things will be between them once the baby arrives.

5.5.9. The impact of HIV on the family

HIV has created an arena for the adults in the system to communicate. It has also introduced secrecy between the adults and Bongani. The use of secrecy has assisted Thandi to preserve her relationship with Bongani. Her belief that Bongani's emotional well-being will be disrupted should he find out about her status has prevented her from educating him and talking to him about HIV.

HIV has made Thandi realise how important her relationship with her grandmother and her son are to her, thus she is spending more quality time with them. In addition, HIV has brought Thandi and Elias closer together as they are able to relate to each other's struggles.

Thandi has also mentioned how she has not allowed HIV to make her afraid that her unborn child will be HIV-positive. She believes that by taking the antiretroviral drug Nevirapine, she'll prevent her baby from being born with a seropositive status.



HIV has also given Thandi's grandmother permission to take care of Thandi and Bongani, thus allowing Thandi to feel safe and secure in her home environment.

5.5.10. Reflections from the observing system

After observing Thandi in the sessions, and then interviewing her, the author was left with mixed emotions. In the sessions, Thandi was always co-operative and took part in the group discussions. However, the author perceived her to be incongruent. For example, during the session on discipline, Thandi said that discussing her son's disobedient behaviour with him was preferential to hitting him. Later, in the same session, a four-year-old child started misbehaving. Thandi shouted at the child and then removed her shoe and tapped the child on the cheek with it. The facilitator found it strange that Thandi chose to discipline another mother's child in this manner, within this particular session.

As a facilitator and researcher, the author was often left with the feeling that Thandi would give appropriate responses in order to please the facilitator/researcher. The terms that come to mind and best describe this process would be "good subject" or "halo effect".

Having said this, it should also be noted that as facilitator, the author was also surprised on more than one occasion by Thandi's behaviour. For example, before the combined sessions, the facilitator hypothesised that Thandi and Bongani were very distant and that Thandi was aggressive in her interactions with Bongani. However, during the combined sessions Bongani and Thandi seemed very close. What the facilitator interpreted as being aggressive behaviour was perceived as being playful and loving behaviour by Bongani.

It should also be mentioned that during the interview process the researcher felt angry with Thandi when she spoke about falling pregnant six months after the intervention and mentioned wanting to abort her child as it was not a planned pregnancy. Listening to Thandi's story stirred up negative emotions for the researcher as she was once again left with the impression that Thandi's behaviour was incongruent. The researcher recalls an incident shortly after the intervention where Thandi had asked the staff working on the Kgolo Mmogo project (in the presence of the researcher) whether: "it is possible to fall pregnant being HIV-positive?" She was informed that it was possible; however, she was told to consult a medical professional before she planned to conceive. It is for this reason that the researcher felt as though Thandi was once again being incongruent as she knew that Thandi was planning to fall pregnant, though Thandi later stated that her pregnancy was unplanned and that was why she was thinking of terminating it. The researcher also felt that Thandi was



being selfish because she had not received medical advice to protect herself and her boyfriend from re-infections as well as her baby from possibly being infected. Also the reasons she gave for contemplating termination and then deciding not to terminate indicated that she was concerned about herself and her own health and not that of her child's.

It was difficult for the researcher to put her emotions aside and to focus on what Thandi was saying without appearing judgemental. Intrapersonally the researcher questioned why Thandi had not consulted a doctor before conceiving when she knew that Elias was also HIV-positive; especially after she was informed to do so? Furthermore, the researcher also questioned what Thandi had learnt about unprotected sex during the session "Living positively – How do I look after myself (Basic Information on HIV/Aids)"?

5.6. CONCLUSION

In this chapter, detailed descriptions were given of each participant with regard to background information, system's components, relationship styles, family rules, boundaries, power, alignments and coalitions and circular patterns of interaction. This was done to ascertain the impact of HIV on family interaction before and after the intervention, and to identify the impact of the intervention in terms of feedback, homeostasis and change. The author's reflections from the observing system were also depicted after each case study.

A discussion of the research findings will be presented in the next chapter.



CHAPTER 6 DISCUSSION OF FINDINGS

6.1. INTRODUCTION

This chapter presents a discussion of the current study findings, which are consistent with the research approach. The findings are summarised and discussed in terms of the participants' similarities and differences and put into perspective, in relation to the reviewed literature.

The aim of the research was not to form generalisations from the findings, but rather to explore and develop a richer understanding of the experiences of South African, HIV-infected mothers and how they perceive the impact of HIV on their family relationships. In addition, the research investigates how the mothers experience their relationships with their children, after participating in a mother-child interaction intervention. The findings show that the two research aspects are interrelated, as the intervention contributed to changing the mothers' perceptions of their HIV status.

6.2. BIOGRAPHICAL INFORMATION

Four of the HIV-positive women who participated in a mother-child intervention were interviewed. The demographics of the selected mothers for this study were as follows: they were black women ranging in age from thirty-one to forty-six, who came from a disadvantaged community in Atteridgeville, Tshwane. The mothers were required to attend the intervention with their children, who were between the ages of six and eleven years. Their marital statuses were, variously: single, married, separated and widowed. The children of the participating mothers were not HIV-infected.

All the women described the great hardship that they had endured in their lives. Some central themes that featured included: poverty and limited resources; unemployment; being raised by single-parent families and/or enmeshed families; being involved in abusive relationships; raising their children as single parents, and living with the physiological and psychosocial effects of HIV.



An important observation that was made during the interviews was that, three out of the four mothers had insight into their circumstances, before and after the intervention. However, when circular questions were used during the interview process, the fourth mother became aware of certain intrapersonal and interpersonal changes.

6.3. HIV IMPACT ON FAMILY RELATIONSHIPS

During the interview process, the mothers spoke about themselves in relation to their families of origin and their nuclear families, focusing specifically on their relationships with their children. The participants also described their relation to HIV and its role in the family.

6.3.1. Personal experience of HIV-infected mothers

After being diagnosed seropositive, the women were initially frightened of HIV; they experienced feelings of despair and devastation, as they believed that they were going to die almost immediately. HIV was perceived to be a "death sentence" that took control of their lives. Three out of the four women went into a depressed state of mood and distanced themselves from their children and other members of their families. Two of the women described feeling very angry with their partners for infecting them. The women also felt uncertain about their futures and were concerned about their children's futures. Only one of the mothers who were interviewed, described wanting and needing to reach out to her child at the time of her diagnosis in order to feel comforted. It is unclear from the information obtained how her state of mind and mood were at the time of her diagnosis. All four of the mothers reported having negative feelings, up until they began the intervention, where they finally reached a level of self-acceptance.

Research has shown that, when women are first diagnosed with HIV, many grapple with their new condition and life circumstances. They often think of death immediately (Rohleder & Gibson, 2005) and present with a lack of affect, later displaying emotions of anger, shame, guilt, fear, stress, anxiety, intense sadness or depression, alienation and suicidal thoughts. Being uncertain of their own future and their children's futures is frightening to women; as a result, women often feel feelings of fear, anxiety, hopelessness, depression and stress (Adinolfi, 2000; Coleman, 2003; Couvaras et al.; Kübler Ross, 1969; Phillips, 2003; Van Dyk, 2008). Most women gradually come to accept their HIV status, however these emotional states are interchangeable and women may have moments where they feel guilty and sad, especially where their children's future and well-being are concerned (Mdlalose, 2006).



In addition, women living with HIV are afraid of being discriminated against and worry that they may be isolated and rejected (Van Dyk, 2008). The four women in this study described how HIV had made them fear being judged and discriminated against. They worried that if they would disclose their status others in the community and even some of their relatives, would judge them as being: promiscuous; unfaithful; immoral and incapable of fulfilling their work duties. They were also concerned about the effect that the disclosure of their status would have on their children. People living with HIV generally perceive stigma as being the cause of negative outcomes, thus they isolate themselves from their friends, families and other social networks. It is their perceptions of HIV stigmas that contribute to emotional distress and feelings of depression (Eba, 2007). However, these perceptions may be based on the reflections of other cases where women and children have been discriminated against and ostracized by others in their communities, such as family members (particularly in-laws), peers, teachers and religious institutions (Eba, 2007; Feldman et al., 2002; IRIN PlusNews, 2007b; Khan, 2004; Lambert, 2004 Salmon, 2001; UNICEF, 2006; Van Dyk, 2008; Wiley, 2003) and did not necessarily happen to them personally.

One of the mothers had encouraged her children to be proud of who they are, and taught them not to allow other people's opinions to influence their perceptions of themselves. This correlates with Rohleder and Gibson's (2005) findings, which show that women attempt to resist projected stigmas from others by separating these from their own identities. One of the other mothers in the current study described how she had to conceal her illness from her employer and needed to convey an image of good health, especially after one of her employer's clients reported seeing her at the immunology clinic. To avoid losing their jobs and to prevent stigmatization (Salmone, 2001; Van Dyk, 2008), many women resort to concealment strategies such as drinking their medication in secret (Mills, 2006) or falling pregnant to portray being healthy (Craft et al., 2007).

The same woman however had not allowed HIV to frighten her when she had fallen pregnant. She was also confident and hopeful that by taking Nevirapine her child would be born with a seronegative status.

6.3.2. The impact of HIV on the nuclear family

6.3.2.1. The effects of HIV on the couple's relationship

The findings show that the two of the women felt that HIV played a destructive role in their marriages. These two women expressed having felt extremely angry with their husbands for infecting them with the virus. They were also furious about their husbands' infidelity and very



upset that their husbands had withheld their status from them. Feelings of double betrayal and emotional outrage are common amongst women who have discovered that they had been infected by their husbands (Feldman et al., 2002).

In the course of the interviews the first participant expressed the difficulty that she and her husband had encountered in their relationship after her seropositive diagnosis. She explained that despite tending to her husband and fighting for her marriage, she and her husband had grown apart in the last few years of their marriage. His betrayal hurt her deeply, and she was reluctant to trust him; she also struggled to treat him with respect.

The second woman described the various issues and difficulties that she and her husband had experienced in their marriage. Above all, she resented her husband for infecting her and blaming her for introducing HIV into their marriage. In many cases, women who disclose their status to their partners are often blamed for bringing HIV into their families and infecting their partners and children (Khan, 2004; Maughan-Brown, 2007; Rohleder & Gibson, 2005; Salmon, 2001). This participant said that HIV created an emotional distance between her and her husband; he who would often become intoxicated and demand to have sex with her. This, in turn, led to a cycle of ongoing verbal and physical fighting, until, finally, legal action was taken. Many women who attempt to negotiate safe sex practices or abstain from sexual interaction with their partners to avoid re-infection, are often abused, or subjected to violence, by their partners (Esu-Williams, 2000; Medscape General Medicine, 1999; Whiteside, 2008; Women's International News Network, 2008; UNFPA, 2002).

The third participant stated that, though she and her husband fought constantly about issues not pertaining to HIV, they were at peace with the introduction of HIV into their relationship. She explained that HIV brought her closer to her husband and that she felt supported by him in this regard. Feldman et al. (2002) state that women who have partners with whom they are able to communicate openly, and who have been informed about HIV, are less likely to be blamed and more likely to be accepted by their partners.

Although this participant's husband is supportive of her, he is still averse to taking precautionary measures during intimacy, i.e. he refuses to be tested and he is unwilling to use a condom during sexual intercourse. This participant was concerned that her husband had admitted that he had been sexually involved with another woman whom he wished to take on as his second wife. He insists that the "pulling out method" is sufficient for safe sex practice. According to Gupta (2005a), people with a lower level of education often lack knowledge of HIV/AIDS and are less likely to use condoms during sexual intercourse. Even



though the participant's husband refused to be tested for HIV, the participant did not harbour feelings of anger towards him with regard to the issue of HIV. However, she did evidence feelings of anger regarding his continued relationship with the other women, and his determination to take a second wife. In some cases, HIV is not perceived to be the most devastating event in a person's life, rather it is the social, economic and family consequences that are considered to be more distressing (Ciambrone, 2001).

It is unclear as to how the fourth mother's relationship was with her previous partner, or if she was involved at the time of her diagnosis. It was only after being diagnosed with HIV that she became involved with her current partner. In this relationship, HIV acts as the couple's scaffold and has brought the couple closer together. Both she and her partner disclosed their status to each other prior to their involvement. In this study, this was the only male who had been tested and had revealed his status to his partner. Very few men reveal their status to their female partners when they discover that they are HIV-positive; they normally only reveal their status when they are very ill (Feldman et al., 2002).

HIV also brought about power struggles which were evident in two of the couple systems. The women attempted to gain "power" from their partners; for example, on discovering that she was HIV-positive, the first participant attempted to gain power by distancing herself emotionally from her husband. She used silence as a means of showing her anger towards her husband and conversed with him only when she was tending to him. The second participant resorted to obtaining a restraining order against her husband and applied for a divorce in order to protect herself and her children from his violent behaviour. In addition, she moved her children to KwaZulu-Natal to prevent her husband from seeing their children.

6.3.2.2 The effects of HIV on the mother-child relationship

Initially, HIV also played a role in the construction of distance within three of the four families. Upon discovering their HIV status, three out of the four mothers refrained from interacting openly with their children. When the first participant revealed her seropositive status to her children, they reacted negatively towards her. She perceived them to be very ashamed of her and believed that they had formed a coalition with their father against her. In turn she distanced herself emotionally from them as she felt that they did not want anything to do with her and that they loved their father more than they loved her. It was only once she had been properly informed about HIV, and when she had adequate knowledge of the implications of the disease, that she "reintroduced" HIV to her children. During this process, the children learnt more about the effects of HIV and became more accepting of their mother. This concurs with Khan's (2005) findings which show that family members that have adequate



knowledge of HIV, and a rich understanding of the implications of the disease, are more accepting and supportive of the infected individual. This process enhanced the mother-child interaction and strengthened the relationship.

Furthermore, HIV initiated a role reclassification in this family system, (after the initial introduction of HIV in the family). For example, the oldest son (28 years old) took on the father figure role in the family and began to fend for the family even while the father was still alive. Also, when this participant took ill, her youngest daughter (aged 12 years at the time) tended to her and took care of her younger brother. She also assumed various responsibilities in the household. Children living with HIV/AIDS-infected parents often take on a parentification role in the family as they need to take care of their sick parents and manage the household (Bauman & Germann, 2005; Minuchin, 1974; Tompkins, 2007).

The second and third participants had intentionally distanced themselves emotionally from their children when they were first diagnosed, as they believed that they were going to die. This was done in order to safeguard their children from being traumatized by their impending deaths. They rationalized their behaviour and way of thinking by believing that if their children were not close to them, then they would not grieve for them when they passed away. These mothers were trying to indirectly control what would happen to their children after they passed away in order to save their children from the pain that they may endure during bereavement. In the third case the mother's withdrawal resulted in the children becoming closer with their father. This was not apparent in the second case as there was limited information in this regard in the research process. However the more the second participant's withdrew from her children the more her children sought her attention, this on going cycle was finally broken when the second participant realised that her children were persistent in connecting with her and she allowed herself to succumb.

Conversely, HIV played a role in reinforcing the mother-child bond in the fourth family. The fourth participant described reaching out to her child (who was eight-years old at the time) for unconditional love and acceptance, when she was newly diagnosed with HIV. Her interactive behaviour helped her form a closer bond with her child and, as a result, she found meaning in her life.

In addition, HIV played a role in keeping secrets within the three of the four families, two of which overlap with the previous group that formulated distance in the mother-chid relationships. Secrets (such as the parental system having HIV and the mothers taking antiretroviral medication), had also been utilized to protect the psychological welfare of the



children and to safeguard the mother's position in the family, as the mothers feared being rejected and isolated by their children. One of these mothers stated that she would regularly fight with her husband when he accused her of introducing HIV into their marriage. Often, the children witnessed their parents fighting, however, according to their mother; they were unaware of what the arguments were about. During the interview, the mother explained how this process caused the children to feel uncertain and insecure within the system, but this was preferable to telling them the reason for the fighting, as this would have caused the children even more distress. Contrary to research findings which posit that secrets in families create unhealthy adjustments (Miller & Murray, 1999; Nagler et al., 1995; Pincus & Fare, 1978), these women believe that secrets protect their children from inevitable emotional devastation.

In all four cases, when the mothers reframed (redefined) their perception of HIV, they were able to adopt a more positive outlook on their lives. As a result, they began to interact more with their children, and their children became more responsive and accepting of their mothers, whether they were aware of their mother's status or not.

6.3.3. The effects of HIV on the extended family

The findings confirm that only two of the mothers were close to their family of origin prior to their diagnosis. The women perceived their extended families to be supportive of them even when they were aware of their HIV-positive status. Because they received full emotional support from their families of origin, these women felt less isolated and more willing to ask their families for help when they were faced with a challenging situation. This helped them to adapt and cope with their circumstances (Van Dyk, 2008). HIV had thus helped to strengthen the relations within these mothers' nuclear and extended families.

In contrast, the other two women described being disengaged from their family of origin prior to their diagnosis and felt that HIV contributed to distancing them further from their families, as they feared being rejected and discriminated against. The rigid boundaries, which were evident in these systems, prevented them from speaking freely with the members of their family and thus they lacked the emotional support that they required, particularly where HIV was concerned. One of these two women, however, had disclosed her status to her mother and younger brother. From their reactions, she perceived her mother to be "too old and too rural" to understand the implications of HIV and her brother "too shy" to discuss this with her. Despite her belief, the participant's mother had shown her supportive behaviour by emphasising her concern for her daughter when she was ill. The other woman chose to



classify some of her family members as family and eliminated others from this group. Despite the fact that certain relatives had been supportive of her in the past, she was still reluctant to discuss her status and circumstance with any of the members of her classified family. In both cases, HIV had prevented these two women from sharing their experience with their family members and had also questioned their ability to trust their extended families.

Women are often blamed by their in-laws for infecting their husbands, and, as a result are rejected from these families (Van Dyk, 2008; Feldman et al., 2002; Salmon, 2001). One of the four mothers had mentioned disclosing to her in-laws and that she had not received any support from them, nor did she feel that she could approach them for assistance. She felt they discriminated against her especially after her husband's death. She was often left feeling as though they blamed her for his death. She stated that they had distanced themselves from her when her husband took ill, and once he passed away, she and her children were completely ostracized and isolated.

Furthermore, HIV created a platform for the adults to communicate in two of the family systems and it assisted in maintaining secrets within two of the other adult subsystems and from three of the children subsystems, within this study. HIV retained an absent but present position in the latter subsystems as these members were unaware of the real underlying reasons for the participants' behaviour i.e. reasons for taking medication, becoming ill and fatigued at times etc.

6.4. THE IMPACT OF THE INTERVENTION ON THE FAMILY SYSTEM

In the interviews, the mothers evaluated the intervention by describing and comparing their relationships with their children prior to and after the intervention.

6.4.1. The mother's personal experience

6.4.1.1. <u>Personal growth and new experiences of motherhood</u>

All four of the mothers in this study noticed that they were more relaxed after having attended the intervention and perceived themselves to be more equipped to handle their stress and to discipline their children. They felt empowered when they acquired knowledge about their illness and learnt how to maintain a healthy lifestyle. The intervention gave them an opportunity to meet with other mothers who were experiencing similar situations, as well as with professionals such as nurses and psychologists, who were able to give them adequate



information pertaining to the management of HIV and the effects of HIV on their relationships. In addition the intervention provided them with a platform to discuss their issues concerning sex and voice their concerns in a safe, supportive environment. The study participants claimed that they had gained intrapersonal insight and became more accepting of themselves and of their circumstances. In supportive and cohesive environments, such as interventions and support groups, where African women are able to support one another and educate each other, either by working together or by learning from each others experiences, personal acceptance can be achieved (Esu-Williams, 2000; Van Dyk, 2008).

After the intervention, the four mothers learnt to let go of aspects that they no longer required such as the belief that HIV was a "death sentence" and that the disease equalled a hopeless future. They also held on to attributes that they viewed as being important to them such as values, traditions and family rules; for example, respecting others remained a cherished value.

All four of the mothers recognised that they and their families had undergone several changes. They learnt more about their relationships with their family members, specifically with their children. In all four cases, the mothers noticed several positive changes in their children and in their interactions with them. They perceived their children to be more confident, responsible and more likely to listen to them. The mothers felt that their children saw them as being more approachable when they had a problem, unlike before the intervention. These changes were also observed by other members of the family.

Previous researchers have defined the family to be an institution and primary place where children can learn fundamental skills, which are essential for developing resilience (Grotberg, 2005; Mallman, 2003). In addition, good quality mother-child interaction and the mother's monitoring of her children's activities are central parental factors that enhance the psychosocial functioning of children (Kotchick et al., 1997).

The intervention perturbed all four of the mothers to accept their status in a more optimistic light. The mothers recognised that they had changed their outlook on life and no longer perceive their status as being a "death sentence". After the intervention, all four women stopped defining themselves in terms of their HIV and they no longer allowed HIV to dictate or control their lives. They became more self-accepting and felt more optimistic about their HIV status as they perceived the disease to be like any other disease. Consequently, they found meaning in their lives. As parental figures, they felt the need to guide their children and ensure that their children were equipped to handle any challenges that they may



encounter later on in life. All four mothers were in agreement that they could assist their children by empowering them with values, goals and problem-solving skills. In addition, all four mothers realized how important their relationships with their children were to them. Thus, they no longer focused on the presence of HIV in their lives, rather they prioritized their children's well-being and what could benefit their children's future. All four mothers agreed that their children could only learn to cope with life's adversities if they were taught the fundamentals within the family system.

The participants also felt that they needed to preserve their family heritage by teaching their children about traditions and religion. Another example would be when one of the mothers continued to store items and important documents into a "memory box" even after the intervention, as a means of ensuring that her children would be provided for when she died. The documents include birth certificates, the title deeds to her house and bank account numbers. Westpheling (1999) states that because HIV-positive mothers are faced with death and terminal illness they are more inclined to make future plans for their children than are mothers who are not faced with the same circumstances.

Thus, by redefining their life goals and recognising a change in their circumstances, these mothers were able to adapt to their new circumstances.

6.4.1.2. Overcoming the issues of disclosure and stigma

The children who attended the intervention remained unaware that the intervention was geared towards people living with HIV. The reason for this was that some of the mothers had not revealed their status to their children. However, the intervention did encourage the women to disclose their status to other individuals, once they felt ready to do so, in order to obtain additional support.

Even though all four women feared the social stigmas attached to HIV and being rejected by those closest to them, they had all disclosed their status to at least one other person outside of their family system, thus, they had a means of attaining external support. For example, they formed relationships with other women at the intervention who have had similar experiences and they also reached out to friends, employers and other women in the community.

6.4.1.3. The issue of disclosing to children

Only one of the four mothers disclosed her status to her children prior to the intervention. Believing that it is vital for her children to be adequately informed and educated about this



matter, she continued to discuss the implications of HIV with her children during and after the intervention. Out of the four mothers she was the only one who perceived her ten-year-old son to be old enough to understand what HIV is and what it entails. Before the intervention, the participant noticed that her son had developed a curiosity about HIV, and she realized that he wanted to acquire more knowledge. Her son had been watching documentaries and programmes about HIV, for example, *Soul City* and *Isidingo*. He has also been listening out for information about HIV at school and had shared what he had learnt with his mother. Shaffer et al. (2001) posit that children who become aware of their mother's condition often acquire more knowledge of HIV/AIDS, which reduces their anxiety and feelings of uncertainty. Such knowledge may counterbalance the possibility of the child experiencing adjustment difficulties.

In contrast, the other three mothers had not disclosed their status to their children, even after the intervention, as they viewed their children to be too young to understand the implications of HIV. They felt that disclosing their status to their children would be too traumatic for them and it could cause them great distress; the mothers feared that the children would think that they were going to die and leave them. Another reason why they didn't disclose their status was to protect their children from being stigmatized by members of their community. Furthermore, they feared being isolated and rejected by their children. These findings coincide with South African studies conducted by Soskolne et al. (2004) and Marcus (1999).

6.4.2. Relationship with children

HIV-infected mothers who are grappling with feelings of guilt, shame, fear and anger associated with their diagnosis could find it difficult to provide adequately for their children's physical and emotional needs as they are often preoccupied with themselves and their new circumstances, which must still be processed. In addition, their physical symptoms, such as fatigue, nausea, diarrhoea and side-effects of potent medication could also complicate their relationships with their children (Westpheling, 1999). Maternal HIV infection may thus disrupt effective parenting and psychological adjustments in children (Reyland et al., 2004). Hough et al. (2003) maintain that the psychosocial and behavioural effects of a mother's HIV status may cause a child to develop inadequate psychosocial skills. From a systemic perspective, it is believed that any behaviour displayed by one member of the family, influences the behaviour of the rest of the family members in a circular manner (Selvini-Palazzoli et al., 1978). In other words, the way the HIV-positive mothers perceive themselves and the manner in which they behave, affect the rest of the family and vice versa. The following factors have been identified as having detrimental effects on children's psychosocial



adjustments: HIV-associated stressors; maternal emotional distress; poor quality of parent-child relationships and a lack of child social support and child coping (Hough et al., 2003).

Prior to the intervention, two of the mothers described battling to maintain clear boundaries with their children. Three out of the four mothers perceived their relationships with their children to be distant and complementary in nature, whereby they exchanged opposite kinds of behaviour with their children and their relationships were based on inequality or differences; i.e. one was dominant and the other was submissive. For example in the case of the first two mothers, their dominate behaviour prompted subservient reactions in their children and in turn the children's reactions reinforced their mother's dominant behaviour, causing a circular reaction from which the mother-child relationship became stagnant. The opposite is evident in the third case, wherein the mother held the subservient role and allowed her son to manipulate her. In the fourth case, however, a parallel relationship was evident in the mother-child relationship.

After the intervention, all four of the mothers perceived their relationships with their children as being closer than before and described their boundaries with their children as being clear and firmer. They credited the intervention with having contributed to the amendment and strengthening of their relationships with the participating child. It must also be noted that three out of the four mothers, who had more than one child, felt that the introduction of new interactive methods (new information), influenced their relationships with their other children in a positive manner. These were the same three mothers who were not close to their children prior the intervention; however, during the course of the interviews, they described their relationships with their children as having become symmetrical in nature. Thus, by altering one or two family members' interactive behaviour in a family system, the rest of the family members' behaviour can be altered as their behaviour becomes affected in a cyclic manner (Selvini-Palazzoli et al., 1978). The fourth participant maintained that her relationship with her eleven-year-old son remained parallel, however, she emphasised that their bond had been strengthened.

In addition, the mothers reported that they had spent more time with their children and had engaged in activities such as playing and talking. They had implemented new methods of disciplining their children whereby they allowed their children to first explain what they had done, and then communicated the correct behaviour to them through discussion. Such interaction helped the children develop problem-solving skills. Mother-child relationships that are warm, open, cohesive and supportive in nature; encourage firm parental control and increased child competency, and provide children with a greater sense of security, may



enhance resilience in children (Baumrind, 1978; Luther & Zingler, 1991; Miller & Murray, 1999; Smith & Prior, 1995; Werner & Smith, 1982).

In all four systems, power struggles were evident prior to the intervention. The mothers described how they used to struggle to gain power in their relationships with their children. All four mothers implemented shouting and beating as disciplinary measures in order to reinforce their authoritative position within their relationships with their children.

The use of "power" in these systems, prior to the intervention brought about insecurity and uncertainty in the relationships between the first three mothers and their children. These mothers and their children were unaware of how to interact or engage with each other and often used incongruent communication which caused misinterpretations. For example, the mothers tried to protect their children by pushing them closer to their fathers, but they also wanted their children to respect them and listen to them. This circular pattern of interaction created a double bind for the children whereby they felt rejected and wanted, simultaneously. The children did not know how to relate to their mothers, and consequently the mothers perceived their children's behaviour as becoming progressively more disobedient, leaving the mothers feeling more frustrated and less needed.

In contrast to the above description the fourth mother felt that she needed to bring her son closer to her and did not push him away. However, she had to implement the same disciplinary methods as the other mothers, which would often not work.

At this stage, the mother-child relations became stuck. The mothers stated that it was only after they had attended the intervention that they were able to obtain new information (regarding disciplining methods and creating mother-child bonding time) which offered them an understanding of their current circumstances in terms of the interactive patterns which maintained their "problem", (i.e. not understanding their children's behaviour), which in turn inhibited them from being able to discipline their children effectively and ultimately created a distance in their relationship.

By believing that their children's previously "disobedient" behaviour was merely an attempt to get their attention, the mothers managed to reframe the "problem" and were able to introduce a new, paradoxical solution to what they defined as being the "problem" that existed in their relationships with their children. In so doing, they managed to change the rules that govern their relationships with their children. They have also broken the interactional cycles and solutions that maintained the original problem behaviour.



From the findings it can be deduced that the intervention educated the mothers and nudged them to utilize effective methods of interaction in order to bridge the relationship gap between mother and child. All four of the mothers realized that shouting and "beating" did not help when disciplining their children. In addition, all four mothers admitted that they would resort to these measures as a means of relieving their own frustrations. All four mothers believed that they needed to dedicate time to discussing things with their children in order for their children to learn from their mistakes. Furthermore, they recognized that they needed to spend time with their children and play was utilized as a way to educate their younger children. Consequently, after the intervention, support and open communication were two important rules that were introduced into all four of these families.

6.4.3. Relationship with partners

The findings do not show that any significant changes took place within the couple systems, nor do they show that the intervention contributed to any changes. It is evident that, after the intervention, only one of the four mothers indicated that she and her partner had resolved their issues and were more content. She stated that she tried to implement what she had learnt during the intervention into her relationship, for example, the couple spent more time discussing their differences and tried to communicate more openly and honestly with each other. The other three participants did not attribute any changes in their relationships to the intervention but change had taken place after the intervention. For example, the third participant compromised her values in her relationship with her husband in order for the fighting to subside. The second participant and her husband ended their fighting with legal action and the first participant was unable to work on her relationship with her husband, as he had passed away prior to the intervention, however she did forgive him for infecting her.

6.5. CONCLUSION

In this chapter a systemic stance was implemented to discuss the findings of this study. The findings provided an in depth understanding and exploration of the effect of HIV on the family interaction and the effect of a mother-child intervention on family interaction from the perspective of the HIV-infected mothers.

In the next chapter, a summary and conclusion of the study, as well as a critique thereof will be presented.



CHAPTER 7 CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

7.1. INTRODUCTION

This final chapter presents an overview of the study's findings in terms of the systems framework, strengths and limitations of the study. Recommendations for future research will also be given, followed by the researcher's reflections on the findings.

7.2. CONCLUSIONS

The current study forms part of the larger Kgolo Mmogo project, which aims to develop, implement and evaluate a mother-child intervention programme through the use of an experimental design. The purpose of the intervention was to enhance and develop parenting skills and improve mother-child relationships within an HIV context. If proven effective, this programme could be replicated in resource-poor communities in South Africa, using trained volunteers as facilitators.

The current study was conducted as part of the formative evaluation of a mother-child interaction intervention, during the pilot implementation of the intervention at the Kalafong Hospital in Tshwane (South Africa). The aim of the study was to describe families that were affected by HIV/AIDS from a systemic perspective. The assumption from this theoretical standpoint is that any behaviour displayed by one member of the family will influence the rest of the family members, who will then react in a manner that affects the rest of the system, thus creating a cyclic reaction (Selvini-Palazzoli et al., 1978). For example, the manner in which the HIV-positive mother perceives herself, and the way in which she interacts or behaves, influences the rest of the family members and vice versa. From this deduction, it was hypothesized that the new information obtained from such an intervention would strengthen the mother-child relationship as well as the other relations in the family system.

The purpose of the study was to answer the following questions: How do HIV-positive mothers experience their relationships with their children once they are diagnosed? And, how does that relationship change, if at all, after participating in a mother-child intervention? These questions were answered by exploring (1) the effect of HIV on family interaction and (2) the effect of the mother-child intervention on family interaction from the perspective of HIV-infected mothers. The basic premise of the study was that mothers would experience an



improvement in their relationships with their children as a result of attending the intervention. Offering the mothers and children encouragement during the intervention would equip them to confront and handle life's adversities and stressors (Mallman, 2003). Consequently, they could also influence their other family members to change their behaviour, as all interactions are circular and, when fed back into the family system, influence the interactions of all the members of the system. This ripple effect could potentially make the family more robust and encourage the family members to rely on each other in times of difficulty, particularly where HIV and AIDS are concerned.

The research was conducted within an interview process and by utilizing circular questions, as set out by the Milan team. The use of circular questions elicited a rich, broad and insightful description of the mothers' experiences of HIV and their relations with their family members, with a specific focus on their interaction with their children prior to and after the intervention. The unique contribution of the study lies in its provision of an in-depth exploration of how HIV-infected mothers perceive and experience HIV both intrapersonally and interpersonally, (especially where their relationships with their families and children are concerned), within a South African context. In addition, the study elicits an understanding of how HIV-positive mothers perceive the impact of a mother-child interaction intervention on their relations with children.

A summary of the research findings was integrated with previous literature and research findings. Many correlates were found to exist between the current study and the existing literature, thereby consolidating this study's findings. The current study findings support the importance of bridging the distance that is created by HIV in family relations, specifically between mother and child. When mothers are newly diagnosed, they become stuck in their own processes, i.e. grappling with and accepting their new circumstances; as a result, they often distance themselves from those they need, and from those who need them most. Coping with an HIV/AIDS diagnosis is very different from coming to terms with another terminal illness in that the perceived social stigmas associated to the disease often isolate infected women and prevent them from obtaining the support that they require from family members, friends, religious organisations, community members etc. Often, women feel that HIV disrupts their relationships with their husbands and children and creates tension, secrets and uncertainty within the family.

Generally HIV-infected mothers tend to keep their HIV status secret from their young children (under the age of ten) as a means to protect them from being discriminated against and experiencing the social stigmas surrounding HIV/AIDS. Some HIV-positive mothers also



believe that, by intentionally creating an emotional distance, they'll prevent their children from being traumatized and feeling sad when they have passed away. Often, the mothers do not realise that their children would benefit from a close relationship that could enhance their resilience later on in life. Because they are so overwhelmed by their status, and angry at the manner in which they were infected, HIV-positive mothers often exercise stringent methods of discipline with their children and avoid spending time with them. The children misinterpret their mother's behaviour and react in a manner that the mother perceives to be disrespectful and disobedient, thus creating a recurring cycle in which both the mothers and the children become stuck.

Because of the taxing effects of HIV on women and their families, the participants emphasized that it was necessary for them to obtain knowledge so that they could deal with their challenges and assist their children to feel a greater sense of security, love and trust in an open, supportive home environment, thus contributing to the enhancement of their children's resilience. The mothers felt that a mother-child intervention helped them to find meaning in their lives, to deal better with their personal experiences of HIV and taught them how to effectively care for their children.

The mothers viewed the intervention as incorporating a holistic approach that focused on their emotional, physical, cognitive and behavioural needs as well as on the needs of their children. Not only did the intervention help the mothers and their children cope with their circumstances and day-to-day activities, it also enhanced their understanding of one another, and strengthened their bond so that they were able to rely on each other in times of difficulty.

After participating in the intervention, the mothers identified several changes in their relations with their participating children. They stated that their interactions with their children had become warmer and more supportive. Their children, in turn, started to pay more attention when they were spoken to, and were more eager to approach their mothers when they needed help. In addition, the mothers and children began spending more time together, engaging in activities such as playing and talking. This new mother-child interaction facilitated a closer bond between the mothers and their children. The mothers also mentioned that they had noticed that their relations with their other children (who did not participate in the intervention), had also been strengthened and that they attributed this to the broader influence of the intervention i.e. that their children had been influenced by the new interaction that was introduced into the family. Thus, the research hypothesis, that the new information obtained from the intervention would strengthen the mother-child relationship as well as the other relations in the family system, was confirmed.



It is clear that a mother-child interaction intervention can benefit families, especially children and mothers, affected by the devastating effects of the HIV/AIDS epidemic and fulfil an important need in providing psychological help. Most of the current efforts to combat HIV/AIDS are focused on prevention and the efforts at treatment level are normally aimed at medical treatment of the infected individual. A mother-child interaction intervention, however, makes provision for the child's well-being; by teaching him/her life and coping skills that he/she can draw on, whilst living with an HIV-infected parent as well as when his/her parent passes away.

Once orphaned, children are not always well provided for; many engage in high-risk behaviours, thus jeopardising their health and safety. Attempts to invest in the future of children, by providing them with the skills that they'll need to handle adversity will prove to be tremendously beneficial for all concerned. Developing new life skills will positively impact the child, first and foremost, but will also benefit the extended family members who normally take on care-giving responsibilities once the parents have passed away. Communities that are struggling to care for large numbers of orphans and external support organisations and state organizations that attempt to provide vulnerable children with psychological and financial support can also benefit, though there is no evidence that teaching life skills at a young age has long term effects.

The researcher believes that, it is not sufficient to focus only on curbing the spread of HIV/AIDS, but it is also vital that, we as a nation manage the disease by looking after those whose lives have been ravaged by AIDS. The researcher suggests that the intervention be extended to include the whole family and extended or replacement caregivers e.g. aunts, grandmothers and volunteers from the community, who are currently looking after AIDS orphans. From the cited literature, it is evident that a stable and consistent caregiver or adult who interacts with a child in a warm, open and secure manner, and offers the child a structured environment, can contribute to the enhancement of resilience (Holditch-Davis, 2001; Skinner Cook et al., 2007). Also, by supporting and training replacement caregivers and strengthening peer support networks, resilience can be fostered in children (Richter et al., 2006; Zimmerman & Arunkumar, 1994).

7.3. LIMITATIONS AND RECOMMENDATIONS

The study is based on various strengths that are indicative of the validity, value and applicability of the study. However, by acknowledging the limitation of the study, the



researcher has taken into consideration the possibility that the validity of the study could have been negatively affected and recommendations for future studies have been made.

Purposive sampling was employed in this study as the aim was to develop theoretical insights specific to only a select population, (i.e. HIV-infected mothers), and not to estimate population parameters; however a more random approach would have been more favourable. A relatively small sample size was used as qualitative research focuses on the depth of a relationship; thus, four participants from a homogeneous group, was thought to be a sufficient sample size (Neuman, 2000). However, the research findings are not necessarily representative of the experiences of all disadvantaged, HIV-positive mothers in the Atteridgeville community, nor can they be generalized to all HIV-infected mothers, in the similar circumstances. The idiosyncratic properties of the sample prevent it from describing the properties of a broader population. However, the sample composition reflected characteristics such as age, gender, lower income group and low education levels that prevail in numerous other South Africa studies. Consequently, the findings present a substantive point of departure for understanding the experiences of some HIV-positive mothers living in underprivileged communities in South Africa. To strengthen the study's findings further, it is recommended that the sample size of four be enlarged to include a far greater number of individuals.

Due to time and language constraints, the researcher did not interview the mothers' children. Ideally, a more thorough investigation into the mother-child relationship could have been obtained. In addition, by interviewing the children with the mothers, the use of circular questioning could have illustrated a deeper understanding of the impact of the intervention on the mother-child relationship and a more methodical evaluation could have been carried out to ascertain whether the children perceived their relationships as more positive. However, the study aimed to explore the experiences of the mothers after they participated in a mother-child interaction intervention, thus the results focus only on the mothers' perceptions of such an experience. Follow-up studies could be done to explore continual patterns or emergent trends, thus providing a clearer picture of the experience.

Since this research is a descriptive study that explores the experiences of a specific sample group, it is difficult to determine how comparable the selected mothers' experiences are to experiences of other HIV-positive mothers from the same or similar communities. Even though in-depth qualitative studies are essential for gaining a nuanced and richer understanding of a group such as the one in this study, the researcher proposes that future studies incorporate a comparison group.



It is important to remember that the sample group considered for this study was recruited at the Immunology Clinic at the Kalafong Hospital where the participants were seeking HIV treatment. Some of these women were newly diagnosed and others were still grappling with their diagnoses. From the findings, it is evident that in both instances, the women were devastated by their diagnoses. It is for this reason that the participants' responses may have been positively biased, as the participants may have been highly motivated to see positive results from the intervention. The mothers were also given the opportunity to interact with other HIV-positive mothers, and thus they could have reached personal insight and overcome their difficulties of their own accord. This is not to say that the intervention had no positive impact on their relationships with their children, as it facilitated the opportunity for interaction to take place. Moreover, the intervention also created the opportunity for personal growth and bestowal of knowledge and education.

Good subject effects, where the participants respond in a manner that they think will please the researcher may have also taken place. The researcher believes that this may have occurred, particularly in the case of the fourth participant.

The researcher, being a subjective being in the world, does not have objective knowledge and for this reason the descriptions are limited by the researcher's own paradigm and methodology (Becvar & Becvar, 2002). Consequently, the manner in which the researcher viewed and interpreted the mother-child interaction patterns, and the impact of HIV on the family may have altered these phenomena. Another independent researcher may have interpreted the same study with the same participants quite differently. Thus, the punctuated findings should not be regarded as absolute truth. Rather, they should be viewed as part of the truth, since everyone in the system is entitled to their own concept of what they consider to be true in relation to the context of the problem or situation.

It is important to mention here that, in keeping with the systemic stance; the researcher reflected on her own assumptions and moral prejudices (Cecchin et al., 1994; Hoffman, 1988; 1991) throughout the research process and shared these with the reader in order to illustrate the impact that the research process and participants had on her. More importantly, the researcher utilized the reflection process as an attempt to avoid influencing the research process and to prevent the validity of the data from being compromised (McMillan & Schumacher, 2001).

From a second-order perspective, the study did not only compare and categorize the mothers and their families; it also took each participant's unique experience into



consideration. It is important to remember that the systemic concepts, used to analyse the data, act as useful guidelines. However there is a risk that these guidelines may be misinterpreted as reality or as a true description of the family; as a consequence, the family may come to adopt or accept this description as well, converting it into a self-fulfilling prophecy (Becvar & Becvar, 2002).

Furthermore, there is a danger in using categories to punctuate the family in relation to the impact of HIV and the intervention. The reason for this is that the findings could be misconstrued as being positivistic or linear with the intensions of pigeon holing the families into narrow categories and eliminating the idiosyncrasies of the unique families that were selected for this study. From a second-order perspective, however, these categories are necessary to understand the circular effects of a system in relation to its defined problem. Second-order cybernetics perspective does not reject the linear or first-order perspective, rather it builds on it. As a researcher working from this perspective it should be recognised as a part of reality which may be relatively useful. By maintaining this stance, one is not restricted to accepting a theory or a piece of research for practical purposes without asserting it to be true (Becvar & Becvar, 2002).

From this perspective, the use of qualitative research employed in this study pursues common characteristics across the mothers' experiences and assists in the generation of a fundamental insight into the mothers' subjective experiences. But, these commonalities do not necessarily translate into normative criteria as is the case in quantitative research. Qualitative research recognises that facts, observation and meanings are theory-dependent and it does not aim to rigidly control certain variables, as all variables are perceived to be equally important. A qualitative approach views the obtained data as valid only under the unique conditions of the implemented intervention, at the Kalafong Hospital, during the twenty-five week intervention and during the ten months after the intervention. In addition, qualitative research takes the history of the family into consideration in order to determine whether change has occurred (Becvar & Becvar, 2002). To overcome this limitation, both qualitative and quantitative methods could be used. The benefit of this is that, various types of information can be obtained which complement one another and could strengthen the study.

Very few studies have investigated the impact of HIV/AIDS on mother-child relationships, and have attempted to strengthen the mother-child relationship within the context of



HIV/AIDS. Thus, the researcher views this study as being the foundation for future research in these areas.

By exploring the unique experiences of the participating HIV-infected mothers into consideration the mother-child intervention is considered to be an effective programme that contributes in strengthening the mother-child relationship. Furthermore this study elicits awareness concerning mothers and children in disadvantaged South African communities that are infected and affected by HIV/AIDS. This study also contributes to educating healthcare workers and enriching their understanding of the impact that HIV has on families in the South African context.



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APPENDIX A: Information letter and consent form to participate in the Kgolo Mmogo



Principal Investigators: Irma Eloff, PhD
Brian Forsyth, MB ChB

University of Pretoria Ethics Committee #:144/2005 Yale University HIC#: 0510000762

KGOLO-MMOGO PROJECT



Tel no: 012 373 1077

Fax no: 012 373 1078

Kalafong Hospital,
Clinical Building,
MRC-Unit for Maternal and Infant
Health Care Strategies,
Private Bag x396,
Pretoria 0001



CONSENT FOR PARTICIPATION IN A RESEARCH PROJECT

A RESEARCH PROJECT OF THE UNIVERSITY OF PRETORIA AND YALE UNIVERSITY SCHOOL OF MEDICINE

Study Title: Promoting Resilience in Young Children

Principal Investigators: Irma Eloff, PhD & Brian Forsyth, MB ChB Funding Source: National Institute of Mental Health (USA)

Parent Form

Invitation to Participate:

You and your child are invited to participate in a research project that is aimed at finding out whether a program that provides information and support to women who have HIV can help build resilience in their children. When we use the term building resilience, we mean helping their children to feel better about themselves and giving them greater strength and abilities to cope with stresses. You and your child have been invited to participate in this project because of your experience with having HIV and because your child is the right age for the study.

In order for you to decide whether or not you wish to be part of this research study, you should know all about the possible benefits and risks. This consent form gives you detailed information about the study. A member of the research team will discuss it with you, and this discussion will include all aspects of the study: its purpose, what will happen, and the possible benefits and risks. Once you understand the study, you will be asked if you wish to participate; and if so, you will be asked to sign this form.

Description of the Project

If you agree you will be assigned to one of two groups. The group you are in will be assigned by chance. This means that you will be given a number and through a random process, you will have a 50-50 chance of being in one group or the other.

If you are in the <u>first group</u> we will ask you to take part in an individual interview at four different times (standard care group). You will have access to the standard care that will be provided to all people participating in the study. If you are in the <u>second group</u> we ask you to come for the interviews and support groups.

Description of the interviews

Whether or not you participate in the support groups, we would ask you to take part in an interview at three different times -- at the beginning, then again after 6, 12, and 18 months. The interview takes about two to three hours and includes questions both about yourself and also about your child. The questions include such things as how much support you feel you are getting and how you are coping. If for any reason you find the interview too long to do at one time, you are free to choose to stop in the middle and continue it at a later time. If your child is aged six to ten years, we will invite your child to participate in interviews at the same time as you. The interviews will include questions considered appropriate for young children, and will last about 1½ hours. Most of the questions come from other studies and are asked in ways that allow children to express their emotions and other feelings that have to do with their self-esteem. We realize that children may find it difficult to participate in something that takes a long time and therefore have a number of techniques to improve this experience. Both you and your child will be given the option of declining to answer any individual questions. During the interview with your child your HIV status will not be mentioned. The person completing the interview will tell your child that this is a study looking at "how children develop



Principal Investigators: Irma Eloff, PhD University of Pretoria Ethics Committee #:144/2005 Brian Forsyth, MB ChB University HIC#: 0510000762

strengths" and there would be no mention of HIV. We also would like to call you between each interview, at 9 and 15 months to check up on how you are doing. This will be a very short interview (about 5 minutes). If you are in the standard of care group, we will also call you 3 months from today.

Because it is helpful to get information from other people who know your child well, we would also invite you to have others, such as a relative and your child's teacher, complete separate evaluations. We are sensitive, however, to the fact that you might not want this to be done, and we would only request this if you wish it to happen and you give separate consent for this to happen. If this were to be done, the person completing the evaluation would be told this is a study looking at "how children adapt and develop strengths" and there would be no mention of HIV. You are free to participate in the study whether or not you invite others to complete evaluations about your child.

If you are in the second group we would ask you to take part in the interview process as described above. In addition we would ask you and your child to attend a weekly support group.

Support program

If you are invited to participate in the support program, this would involve you attending weekly support groups with other HIV positive women over six months. Each session lasts about two hours and covers a specific topic. Group leaders help members talk about things that affect them and help members understand the needs of their children and how children may be helped to be more resilient. Children between the ages of 6 and 10 can also attend a group with other children at the same time as their mothers, and there will be a daycare for younger children. Some of the sessions will be joint sessions where mothers and children get the opportunity to do activities together. If you were unable to attend the group because of illness, a staff member of the Kgolo Mmogo project will visit you at home and provide you with similar support and information. Your child would still have the opportunity to join the group.

Risks regarding confidentiality

There are no known risks to being in this study except those that relate to confidentiality of information. All information obtained during the course of this study is strictly confidential. Once information is collected, your name and your child's name and other identifying information such as addresses will be removed and the form and any computerized information will be identified by a code number only. The list of names and code numbers will be kept in a locked cabinet to which only the researchers will have access.

We won't give out any names or contact information to anyone who is not directly working on this study unless there is concern about a serious psychiatric problem, the threat of violence to yourself or others, or concern about child abuse. If such a concern arises we will make every effort to discuss the action with you before taking action.

During group discussions some people may reveal personal information to others in the group. Study participants will be instructed to keep private all information that has been shared. Because this project includes helping parents communicate with their children in an age-appropriate manner about important things in their lives, we expect that some parents will tell their children about their HIV and children might share this information with others. Disclosure about your own HIV status, however, is something for you to decide upon. Program staff will not disclose or discuss your HIV status, except in instances in which you wish this to happen and have provided your written permission. Staff is trained in how to maintain confidentiality when children raise questions about HIV. If you are selected to participate in a support group but do not want your child to attend the children's group, you can choose to do this and then, if you change your mind your child could join the group later. Any scientific reports using data from this study will not include information that identifies you as a subject.

Benefits

The study is designed to find out whether this type of program benefits parents and children but we do not know whether you or your child will benefit personally from participation in the study.

Financial Considerations

To reimburse you for your travel costs and the time spent doing the interviews, you will be given 50 rands for completing each interview and your child will be given a small toy worth about 10 rands.

What are my rights as a participant in this study?

The participation of you and your child in this study is entirely voluntary and either you or your child can refuse to participate or stop at any time without giving any reason. If you decide not to participate or withdraw from the study this will not affect you in any way and will not affect the

Principal Investigators: Irma Eloff, PhD Brian Forsyth, MB ChB UNIVERSITY OF PRETORIA
UNIVERSITY OF PRETORIA
UNIVERSITY OF PRETORIA
University of Pretoria Ethics Committee #:144/2005
Yale University HIC#: 0510000762

care you or your child receives. If you decide to be in the study, you can leave blank or refuse to answer any questions that you don't want to answer.

Has this study received ethical approval?

This study has been approved by both the Health Sciences Ethics Committee of the University of Pretoria and the Human Investigation Committee of Yale University School of Medicine. The study is in accordance with the declaration of Helsinki (Last update: October 2000), which deals with recommendations guiding biomedical research involving human subjects.

Questions

Please feel free to ask about anything you don't understand and consider this project and the consent form carefully – as long as you feel is necessary – before you make a decision.

Informed Consent

I hereby confirm that I have been informed by the study personnel, about the nature, conduct, risks and benefits of this study. I have also read or have had someone read to me the above information regarding this study.

I am aware that the results of this study will be anonymously processed into a report.

I may, at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study and agree to the participation of my child.

Child's name	(Please print)			
Name of Subject (parent)	(Please print)			
Subject's signature	Date			
I, herewith confirm that the above person has been informed fully about the nature, conduct, and risks of the above study.				
	risks of the above study.			

If you have any further questions about this study, you can call the study investigator, Dr. Irma Eloff, PhD at: 012-420-3751. If you have a question about your rights as a participant, you can contact the University of Pretoria Health Sciences Ethics Committee at 012-339-8612.

IRB NUMBER	00002235
FWA	00002567

THIS FORM IS NOT VALID UNLESS THE FOLLOWING BOX HAS BEEN COMPLETED IN THE HIC OFFICE

THIS FORM IS VALID ONLY FROM:		
UNTIL:		
University of Pretoria PROTOCOL #: 144/2005		
Yale University HIC#: 0510000762		
INITIALED:		



APPENDIX B: Information letter and consent form to participate in the current study (English and Sepedi versions)





Pretoria 0002 Tel (012) 4204111 Faculty of Humanities 07/07/2009

Dear Participant

This letter is an invitation to participate in a study I am conducting as part of my Master's degree in the Department of Psychology at the University of Pretoria under the supervision of Prof Maretha Visser. I would like to provide you with more information about this project, and what your involvement would entail if you decide to take part.

This research is an extension of the Kgolo Mmogo project in which you and your child participated last year. In this research, we would like to find out how participation in the group influenced your relationship with your child. This research is important to understand how the intervention impact on your family relationships and whether changes should be made in the intervention to assist mothers with HIV. Your participation in this study is very important because we would like to hear from you how you have experienced your relationship with your children before and after you participated in the group.

Participating in this study is voluntary and it will involve an interview of approximately one and a half hours, which will take place at Kgolo Mmogo at the Kalafong Hospital in Tshwane. You may decline to answer any of the interview questions if you so wish and you may decide to withdraw from this study at any time without any negative consequences. With your permission, the interview will be audio recorded to facilitate the data collection process. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the contents of our conversation and to add or clarify any points that you wish. We will reimburse you for your travel costs and the time spent doing the interviews. You will be given R50, 00.

All information you provide is considered completely confidential, your name will not appear in any dissertation or report resulting from this study. With your permission, anonymous quotations may be used. Data collected during this study will be retained for fifteen years in



a locked safe and only researchers associated with this project will have access. There are no known or anticipated risks to you as a participant in this study. However, should you wish follow-up sessions due to this study, you will be referred to an appropriate service.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at $082\ 343\ 1954$ or you can also contact my supervisor, Prof Maretha Visser at (012) 420-2549.

I would like to assure you that this study has been reviewed and received ethical clearance through the Ethics Committee by the faculty of Humanities *at the University of Pretoria*. However, the final decision about participation is yours. I hope that the results of my study will be of benefit to other mothers in the same situation as you. I look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Anastasia Antoniades

CONSENT FORM

I have read the information presented in the information letter about a study being conducted by **Anastasia Antoniades**, under the supervision of **Prof Maretha Visser**, of the Department of Psychology at the University of Pretoria. I have had the opportunity to ask questions related to this study, to receive satisfactory answers to my questions.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the dissertation and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty, by advising the research and that this project has been reviewed by the Faculty of Humanities, and received ethical clearance through, the Ethics Committee, at the University of Pretoria.

I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Supervisor of the Project, in the Department of Psychology, Prof Maretha Visser on (012) 420 – 2549.



With full knowledge of all abovementioned.	, I agree, of my own free will, to participate in	
this study. YES NO		
I agree to have my interview audibly records	ed. YES NO	
I agree to the use of anonymous quotations in a dissertation or publication that comes of		
this research. YES NO		
Participant Name	Participant's Signature:	
Researcher: Anastasia Antoniades	Researcher's Signature:	
Signed at:	day of2007	
<u>oigned at</u> On this the	2001	





Pretoria 0002 Tel (012) 4204111

Faculty of Humanities

07/07/2009

Motšea Karolo

Lengwalo le go mema go tlo tšea karolo mo dithutong tše ke di dinago e le karolo ya Master's degree ya ka mo lefapheng la Saekhelotsi mo Univesitying ya Pretoria ka tlase ga thlokomelo ya Profesa Maretha Visser. Ke nyaka go gofa tsebo ka mokgatlho le kgolagayo ya gago ge o nyaka go tšea karolo.

Thuto ke tšwetso pele ya mokgatlho wa Kgolo Mmogo yeo o kilego wa tšea karolo go yona, wena le ngwana wa gago ngwageng wa go feta. Mo thutong ye re nyaka go tseba gore go tšea karolo ga gago mo mokgatlhong go bile le mohola mo kgolaganong ya gago le ngwana wa gago. Mo thutong ye go bohlokwa go kwešiša gore thuto ye e bile le mohola mo kgolaganong ya lelapa la gago goba go swanetše go dirwe diphetogo mo thutong go thuša bomma bao ba phelang ka twatši ya HIV. Go tšea karolo ga gago mo thutong ye, go bohlokwa ka gore re nyaka go kwa ka wena gore o bona bjang kgolagano ya gago le ngwana pele le morago ga go tšea karolo mo mokgatlhong.

Go tšea karolo mo thutong ye ke ka boithaopo bja gago, go tlo ba le dipotšiso tšeo di ka go tšeang iri le metsotso e masometharo. E tlo diragala kua Kgolo Mmogo bookelong bja Kalafong go la Tshwane. O tla kgopelwa go araba dipotšišo tšeo o tla bego o di botšišwa, ge o nyaka.

Ge o sa nyake go tšwela pele ka thuto ka nako engwe le engwe go ka se be le bothata. Ka tumelelo ya gago poledišano ye e tla gatišwa go kgobokantša dintlha. Sebakanyana morago ga poledišano ke tla go romela lephephe leo le ngwadilwego ka ga poledišano ya rena, re go fe monyetla wa go tlatša goba go hlatholla dintlha go ya le ka go rata ga gago. Re tla go hlatswa matsogo ka tšhelete ya go namela le nako yeo o e tšerego go tlo dira dipoledišano. O tlo fiwa masome a mahlano a dirata (R 50-00).



Tsebo yeo wena o re filego yona, tseba gore ke sephiri, leina la gago le ka se tšwelele ge re hlagiša goba re efa dipoelo ka thuto ye. Ka tumelelo ya gago go na le mokgwa wo re o šomišago go se hlagiše maina a gago. Tsebo ka moka ye re e hweditšeng mo dithutong tše e tlo lotwa mengwaga e lesomehlano. Go dumeletšwe fela bakgokaganyi ba thuto ye. Ga gona tsebo goba mathata ao re a tsebago ge o tšea karolo. Ge o na le kgahlego ya go tšwela pele mo thutong ye, o tlo romelwa mafelong ao a swanetšego.

Ge o na le dipotšiso ka thuto ye goba o nyaka go hwetša tsebo yeo e tletšego go go thusa go tšea sephetho ka go tšea karolo, o ka nteletša mo 082 343 1954 goba o ka leletša motlhokomedi (Mofahloši) wa ka Maretha Visser mo (012) 420 2540.

Ke na le kgonthišišo ya gore thuto ye e lebeletšwe gape ya amogelwa ke komiti ya Ethics ka lefapheng la Humanities ko University ya Pretoria. Le ge go le bjalo sephetho sa go tšea karolo ke sa gago. Ke tshepa gore dipoelo tša thuto ye di tlo thuša bomma ba bangwe bao ba lego seemong sa go swana le sa gago. Nka thabela go bolela le lena le go le leboga pele ga nako, ka thušo ya lena mo thutong ye.

We lena

Anastasia Antoniades

Foromo ya go tšea karolo

Ke badile tsebo yeo e hlagišitšweng ka thuto yeo le e filego ke Anastasia Antoniades ka fase ga tlhokomelo ya Prof Maretha Visser, wa lefapha la Psychology mo University ya Pretoria. Ke bile le monyetla wa go botšisa dipotšišo mabapi le thuto ye, le go hwetša dikarabo tšeo di kgotsofatšago tša dipotšišo tšaka.

Ke a tseba gore ke na le boikgethelo bja go dumela gore poledišano e gatišiwe go kgonthišiša ga dikarabo tšaka.

Ke a tseba ka diripana tša poledišano tšeo di ka šomišwago goba tša gatišwa mo thutong ye ka tsebo ya gore maina a ka se hlagišwe.



Ke tsebišitšwe gore nka tšea karolo goba ka lesa nako engwe le engwe ka ntle ga kotlo, ka go tsebiša kgolaganyo gore thuto ye e lekotšwe ke Faulty of Humanities gape ya hwetša Ethical Clearance go tšwa Komiting ya Ethics mo Universiting ya Pretoria.

Ke tsebišitšwe gore kena le ditlaleletšo goba dingongorego ka go tšea karolo mo thutong ye. Nka leletša mothlokomedi wa thuto ye mo lefapheng la Psychology, Prof Maretha Visser (012) 420 2549.

Ka tsebo yeo e tletšego ye ke e filwego ka godimo, ke a dumela, ka thato yaka, go tšea
karolo mo thutong ye.
□ Ee □ Aowa
Ke a dumela gore dipoledišano di gatišiwe.
□ Ee □ Aowa
Ke a dumela gore go dirišiwe mokgwa wa go se hlagiše maina, ge go gatišwa go ba go tšweletša ya thuto ye.
□ Ee □ Aowa
Motšeakarolo: Kgatišo ya motšeakarolo:
Mokgokaganyi: Anastasia Antoniades Kgatišo ya Mokgokaganyi:
Kgatišo mo: Letšatši Kgwedi Kgwedi
Ngwaga



APPENDIX C: Interview Schedule

INTERVIEW SCHEDULE

- 1. Tell me a bit about yourself?
- 2. Are you married or in a relationship?
- 3. How many children do you have?
- 4. Do your children stay with you?
- 5. Who else stays with you?
- 6. Do you find it easy to talk to your family about things that bother you?
- 7. How was your relationship with your child/ children before you were diagnosed as HIV positive?
- 8. How has HIV influenced your relationship with your child/children?
- 9. How was your relationship with your child or children before you attended the Kgolo Mmogo project?
- 10. Is it still like that?
- 11. What is your explanation for the change / for it remaining the same?
- 12. Who in your family would agree and who would disagree with you?
- 13. What sense do you make of the way your relationship was with your child or children at the time?
- 14. How do you see your relationship with your child/children to be in the future?
- 15. Who was closest to whom in the family before the intervention?
- 16. Who is closest to whom in the family now?
- 17. Who was the least closest in the family before the intervention?
- 18. Who is the least close now?
- 19. Who spends the most time with whom?
- 20. Who would be closest in the future?
- 21. What is your reason for the likelihood that this would happen?
- 22. Who would agree or disagree with you?
- 23. What things did you do together as a family before you joined Kgolo Mmogo?
- 24. What things do you do together as a family now that you have completed the project?
- 25. What have you learnt about yourself during the project?
- 26. What do you think you have learnt about your child?
- 27. What do you think that your child have learnt about you?
- 28. How has this new information impacted on your relationship with your child?
- 29. Who else in your family has noticed this new information / impact on your relationships?
- 30. What have you implemented into your relationship from the intervention?
- 31. How is the different than before you joined Kgolo Mmogo?



- 32. What is your explanation of this?
- 33. What does it mean to you that your (behaviour) has changed / remained the same?
- 34. Has there ever been a time where you were to ill to clean your house, cook or care for your children?
- 35. What happened when this occurred?
- 36. Where was your child/ children at this time?
- 37. What did your child/ children do?
- 38. And then what happened?
- 39. How did s/he respond?
- 40. Is it still this way?
- 41. When they don't notice what happens?
- 42. How do you react?
- 43. Who would agree with you that this is what happens?
- 44. What does it mean to you when they react this way?
- 45. Who acts most upset when you are ill?
- 46. Who is the most involved in the situation?
- 47. Do you feel that they are supportive of you?
- 48. In what way are they supportive / not supportive?
- 49. Who knew about your status before you came to Kgolo Mmogo?
- 50. Did you tell anyone during your time on the project or after the project ended about your status?
- 51. What does it mean to you for this person to know of your status?