

**PROCESSES THAT INFLUENCE THE EXPERIENCES OF CHILDREN
LIVING WITH MOTHERS THAT HAVE HIV
TWO CASE STUDIES**

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ABSTRACT

Maternal HIV-infection is considered to be a threat to the psychosocial development of AIDS-affected children. In South Africa, AIDS-affected children may be particularly vulnerable due to the unprecedented effects of the HIV/AIDS epidemic on the breakdown of family and community resources in already disadvantaged communities. The aim of this study was to explore the contextualised experiences of two children living with mothers who have HIV by conducting two case studies. Mother-child dyads were recruited from local HIV/AIDS centres and informed consent was obtained. The mothers were in the minor symptomatic phase of HIV-infection and the children were uninfected and aged between 10 and 12 years. Through semi-structured interviewing, the mothers provided background and contextual information about the children. Play techniques were used in the child interviews to encourage the introduction and exploration of issues salient to the children. Play facilitated engagement around sensitive and potentially anxiety-provoking material. A key issue for the children was their concerns about the anticipated deaths of their mothers. The children held misconceptions about the transmission of HIV/AIDS. They feared HIV/AIDS and expected that others would have negative perceptions of them. Family processes such as secrecy and avoidance around HIV/AIDS-related issues were understood to perpetuate the children's fears and false beliefs in a broader community context that stigmatised HIV/AIDS. It was argued that the mothers' shame over HIV-infection and their need to protect their relationship with their children compromised their ability to communicate openly with their children and to offer them meaningful emotional support. Limited parental involvement was identified as the key contextual process that engendered vulnerability in the children, as they were isolated within and beyond the family. Recommendations to address the processes that engendered vulnerability in the children are discussed.

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CHAPTER ONE

1.1 INTRODUCTION

1.1.1 HIV/AIDS and childhood in South Africa

Globally HIV/AIDS has been recognised as the greatest threat to child development (Smart, 2000). HIV is an acronym referring to the human immunodeficiency virus that causes a syndrome of opportunistic diseases, referred to as Acquired Immune Deficiency Syndrome or AIDS (van Dyk, 2001). In South Africa the HIV/AIDS epidemic has had wide-spread ramifications on the lives of children as they are increasingly left orphaned. Broader implications are evident in the breakdown of extended kinship systems that have traditionally provided surrogate care (Kelly, Parker & Oyosi, 2001). The living circumstances of children affected or infected by HIV/AIDS can be understood as being embedded in a disadvantaged socio-economic context that is being further eroded by the HIV/AIDS epidemic.

In general, the living circumstances of children in South Africa has been described by the first South African supplementary report on the UN Convention on the Rights of the Child (May, 1999 cited in Smart, 2000) as a "racially divided, traumatised, dehumanised and child welfare negligent society". Conditions of poverty are widespread as 61% of the 16.3 million children in South Africa live in poverty (Smart, 2000). Poverty is understood as living below the absolute poverty line of R400 per adult per month (Fox, Oyosi & Parker 2002). Children affected or infected by HIV/AIDS in South Africa are vulnerable to not having their physical, material, educational and psychosocial needs met.

1.1.2 The HIV/AIDS epidemic in South Africa

South Africa, after India, has the fastest growing HIV/AIDS epidemic in the world. Women are at higher risk for HIV infection, with the highest rates of infection corresponding with their reproductive years. This has implications for families and child-care as women head 39% of households (Smart, 2000). Between 1994 and 1997 the number of children orphaned by AIDS increased by 400%. Statistical data predicts that by 2015, 3.6-4.8 million children under the age of 15 or 9-12% of the total population will be orphaned by AIDS-related deaths.

1.1.3 Definitions

South African terminology has grouped children influenced by HIV/AIDS into three categories; namely HIV/AIDS orphans are children under the age of 15 who have lost mothers to AIDS-related causes; infected children are under the age of 18 and are infected with HIV and affected children live in a family in which there are or have been one or more HIV infected family members (Smart, 2000). However, definitional categories are somewhat blurred in that Smart (2000) and Fox et al. (2002) include all three categories of children under the term affected children or children living with HIV/AIDS. In addition, studies on the impact of HIV/AIDS on children lack consistent definitions of their samples and thus confusion may arise as to the referred group (Wild, 2000). In order to achieve certain congruence with the literature, the participants in this research, uninfected children living with mothers who have HIV are termed AIDS-affected children.

1.1.4 Action: The national strategy on HIV/AIDS and children

In South Africa, a national strategy on children and HIV/AIDS is being developed with the purpose of addressing the multi-faceted needs of this group. The Interim National HIV/AIDS Care and Support Task Team (NACTT) (Smart, 2000) has formulated a number of recommendations to address the rights and physical, material, educational and psychosocial needs of affected children, including orphans and infected children. Included in the many interventions suggested is support for affected children in the form of support groups, counselling and the drawing up of guidelines for associated projects. The need for research is underscored in order to guide the implementation of a national strategy (Smart, 2000).

1.1.5 Research on HIV/AIDS and children in South Africa

Although a burgeoning corpus of work is being established on the impact of HIV/AIDS on children, most of this is conducted in the USA (Wild, 2001). The status of research in South Africa is far less developed (Kelly et al., 2001). The literature on AIDS-affected children in South Africa and Africa reveals a gap between practitioners in the field and research. Kelly et al. (2001) state that many intervention programmes are started without guidance from theoretical findings and tend to be based on common sense thinking rather than on the use of previous experience or evaluation. Furthermore valuable knowledge from these initiatives has not been published. There has been no national health survey on children and thus very little is known about children's (below the age of 12) responses to HIV/AIDS. Kelly et al. (2001, p.14) are critical of many the studies that do exist. Both with respect to children and

in other aspects, the authors believe that there is "very little substantive theoretical work orientated towards understanding HIV/AIDS in a South African context". Wild (2001) highlights difficulties with doing research on communities that have been overlooked by traditional psychological research. With regard to children, little is known about culturally informed parental beliefs and expectations. Psychological assessment instruments lack appropriate local norms and qualitative techniques are hampered by the difficulty in eliciting valid data from children on sensitive topics such as parental HIV infection.

In this study, a case method approach was utilised to explore the experiences of AIDS-affected children. It by no means addresses the criticisms of the status of research in South Africa per se. Instead it represents a foray into a largely neglected and undocumented area of research. Through detailed exploration, the lives of two AIDS-affected children were investigated with regard to salient situated processes or factors that mediated their experiences of living with an HIV-infected mother. Factors that played a protective role or that engendered vulnerability were highlighted with a view to making recommendations as to possible areas of intervention.

1.2 CONCEPTUAL FRAMEWORKS

Research on the psychosocial adjustment of AIDS-affected children can be situated within a broader theoretical framework concerned with the effect of stressors on childhood development. The work of Rutter (1988) and Garmetzy (1988) is used to introduce the main concepts and conceptual dilemmas. Contemporary research on contextual influences and the importance of protective and vulnerability processes or factors is reviewed. Application of this conceptual framework is discussed with respect to the literature on the effects of parental physical illness, maternal HIV infection and other AIDS-associated stressors on childhood psychosocial adjustment, as they offer theoretical frameworks from which to understand the experiences of AIDS-affected children.

A note on contextual factors and universality

The mostly USA-based quantitative and qualitative studies offer a perspective rooted in the historical and cultural understandings of that society in general and of psychological practice in particular (Dawes & Donald, 2000). Notions of childhood, the needs and rights of children and child-rearing practices are not necessarily universal. However, findings from research in contexts other than South Africa remain relevant so long as they are not applied uncritically

(Dawes & Donald, 2000; Kelly et al. 2001). A balance needs to be found between learning from other contexts and taking cognisance of what is not applicable to the social, cultural and material conditions found in South Africa. Since a number of cultural communities exist in South Africa, each with their own beliefs and practices, Dawes & Donald (2000) suggest that account should be taken of local knowledge and practices.

1.2.1 Stressors and childhood development

Rutter (1988) identifies four main indeterminate areas in studies concerned with the effect of stress on childhood development. The term stress, the notion of coping and resilience are ill-defined concepts that require clarification. The main conceptual difficulties lie with attempts to develop causal relationships between stressors and dysfunction or adaptation. The basic question to be answered is thus whether there is an association between stressful life events and developmental dysfunction. The bi-directional impact of stressors, the duration of the stressors, acute or chronic, and the nature of the stressors became important conceptual distinctions and gave rise to a number of studies. Rutter (1988) argues that an analysis of the impact of stressors on childhood should examine three factors; namely 1) which features in a child's life 2) may predispose him/her to developing dysfunction and 3) what underlying mechanisms or processes are evident.

Rutter (1988) and Garmezy (1988) discuss a number of events in the lives of children that may be considered as stressful. In all such cases the developmental stage of the child, individual characteristics and social context play an important role in how the child experiences and manages the stressor. Lastly, Rutter (1988) proposes that different types of stressors and associated effects can be differentiated according to their psychological meaning and consequences. The individual's cognitive appraisal of an event will strongly influence the experience of such event (Rutter, 1988). 'Stressful life events' remains a broad, conceptually undefined term that refers to the complex and multi-dimensional nature of stressors and the array of individual responses.

Conceptual distinctions between factors or processes that ameliorate against stressors or that increase the effects of stressors have given rise to the protective versus vulnerability model discussed by Garmezy (1988). An interactive relationship exists between stressors and personal attributes in predicting adjustment where protective processes influence adjustment as they interact with the stressor. Contemporary research identifies specific protective factors

and the role they play in promoting competence, or effective adaptation to the environment or reasonable success with major developmental tasks in children, despite exposure to adverse conditions. However, it is important to note that stressors or protective factors do not act on their own. Competence results from complex interactions between the child and his/her world. It may change as the child changes developmentally and/or as the context changes. An important aspect of the research on stress and childhood development is that children have different vulnerabilities and protective systems at different points in development (Masten & Coatsworth, 1998). Concepts and distinctions discussed above are seen and re-examined in research on the relationship between parental HIV infection and child functioning.

1.2.2 Quantitative studies on the impact of parental HIV infection on childhood psychosocial adjustment

Since 1994, research attention in the HIV/AIDS field has focused on the psychosocial adjustment of children affected by HIV/AIDS (Siegel & Gorey, 1994; Wild, 2001). Discussion of the research in this area will focus only on those studies that used samples of AIDS-affected children as opposed to AIDS-orphans. The bulk of early studies in the USA attempted to establish whether AIDS-affected children are vulnerable in unique ways as compared to children whose parents were not ill or those children whose parents had other physical illnesses. Research assumes that AIDS differs from other chronic illnesses in that "the specific constellation and intensity of problems facing families affected by HIV set this disease apart from other contemporary health problems" (Geballe & Gruendel, 1998, p. 50). This assumption is then supported by the identification of AIDS-associated stressors uniquely experienced by this population. Based on these principles, researchers argue that AIDS-affected children constitute a highly vulnerable group and seem to be at risk for psychological distress and unresolved grief that may lead to developmental, behavioural and health problems (Geballe & Gruendel, 1998; Pivnick & Villegas, 2000; Siegel & Gorey, 1994; Wild, 2001).

Wild, (2001) discusses eight studies that use either quantitative or qualitative methodologies to investigate the relationship between maternal HIV status and the psychosocial adjustment of AIDS-orphans and AIDS-affected children. The results vary and are difficult to compare in part because of the lack of methodological rigour and inconsistencies across a number of dimensions such as differences in sample sizes, composition and definitions describing

participants as well as conceptualisations and measurement of psychological adjustment. Of these studies examined only two qualitative studies focused exclusively on children living with HIV infected parents, while a further three descriptive studies used samples comprised of both AIDS-orphans and AIDS-affected children. Wild (2001, p.8) contends that knowledge about the psychosocial adjustment of AIDS-affected children and AIDS-orphans is "based on an intermingling of sound data, less reliable data and clinical observation, and is therefore less secure than might appear at first glance".

Quantitative or comparative studies measured the psychosocial adjustment of children across a number of domains using quantitative psychological assessment measures. Those that focused exclusively on AIDS-affected children will be discussed. Forehand et al. (1997) compared children living with fathers that had haemophilia with children living with fathers that had haemophilia and that had HIV. In this largely white and middle-class sample, children of HIV-infected fathers showed higher levels of internalising problems but did not differ on other measures.

A comparative, multi-variate study was conducted on a sample of African-American children living with HIV positive mothers in disadvantaged socio-economic conditions (Forehand et al., 1998). This study is notable for two reasons; it was the first that investigated the impact of maternal HIV infection on the psychological adjustment of non-infected children and it introduced the idea of considering the role of contextual factors on this relationship. Children were compared to a matched sample of children whose mothers were uninfected. The results show that although children of HIV-infected mothers showed psychosocial difficulties in multiple domains, such as internalising and externalising problems, and less social and cognitive competence, the children from the matched sample similarly showed psychosocial difficulties. Children of HIV infected mothers simply scored worse than the control group. Forehand et al. (1998) explain these results by suggesting that the multiple stressors experienced by the children in both groups such as community violence, poverty and single-parent households might contribute to their findings. Maternal HIV infection was considered an additional stressor in an already stressed context. As such, differences between the children could not be attributed solely to maternal HIV infection.

Forehand et al. (1998) suggest a number of potential mechanisms whereby maternal HIV infection can be associated with child psychosocial adjustment difficulties. Some may be

unique to HIV infection, others may share features found in families with parental chronic illness and others may be common to families affected by other stressors. For example, results from the Forehand et al. (1997) study showed that the HIV status of the fathers rather than the severity of the haemophilia had a significant impact on family functioning. Fathers that were HIV positive showed poorer psychological and physical functioning, poorer mother-child relationships were found in this group as well as greater economic pressure on the family and less support from outside the family for both spouses.

1.2.3 Qualitative studies describing the impact of parental HIV infection on children

Qualitative studies encouraged AIDS-affected children and adolescents to give their views and perspectives on living with HIV-infected parents. In particular, a study conducted by Pivnick & Villegas (2000) on children and adolescents aged between 10 and 18 highlighted the central role of home circumstances on how children coped with parental HIV infection. Many of the children came from homes in which parents had abused drugs. As a result they had been chronically neglected, physically and sexually abused and at times they had experienced homelessness. For the most part the children did not have access to support of any kind. This context played an important role in understanding the children's reported experiences that included difficulties in communication with their parents, expressing feelings about the impending death of the infected parent and planning for the future. Although many of these children reported symptoms of depression, chronic feelings of sadness, despair, suicidal ideation, somatization, sleep disorders and nightmares, Pivnick & Villegas (2000, p.121) suggest that this symptomatology cannot be directly related to parental HIV infection. Rather HIV infection exacerbates long-standing difficulties and "AIDS, for these children, is the last stressor in a long chain of issues". As the above studies indicate, AIDS-affected children may be exposed to a number of stressors over and above those related to HIV/AIDS.

1.2.4 Underlying processes

According to the analysis posed by Rutter (1988), research in this area has identified a number of stressors or features in lives of AIDS-affected children life that may predispose them to maladjustment. As to the identification of underlying mechanisms or processes, little research has been conducted (Wild, 2001). However, one study conducted by Steele, Forehand and Armistead (1997) used findings from research on parental physical illness to test a model demonstrating the importance of family processes.

The model tested the influence of family processes and child coping strategies on the relationship between parental chronic illness and child internalising problems. The pathways by which parental chronic illness were found to impact on children's functioning included the emotional distress of the parent, parent-child relationships and the marital relationship (Steele et al., 1997). Data revealed that depressive symptoms reported by both parents directly predicted child internalising difficulties. In addition an indirect pathway of influence was noted in that problems in the parent-child relationship and the use of avoidant coping played an intermediate role in predicting internalisation outcomes in children. Increased relationship problems predicted the increased use of avoidant coping.

1.2.5 Research on parental chronic illness as a childhood stressor

Studies on parental physical illness and child functioning provide a number of findings that suggest underlying mechanisms and processes that might mediate and moderate child adjustment. A review of this literature (Armistead, Klein & Forehand, 1995) found six studies using independent samples to investigate the impact of parental physical illness on child functioning. The authors conclude that the literature in this area is too sparse and inadequate to describe the relationship between specific types of illness and different areas of child functioning. Nonetheless, studies have attempted to identify variables in children that influence the impact of parental illness on their functioning. In these studies the relationship between selected variables and child functioning is examined within a group of physically ill parents and their children. Armistead et al. (1995) caution against drawing conclusions from the six studies reviewed because of differences between type of illnesses studied and the fact that the variables identified were found to be associated with childhood functioning in only one or two studies. The results are not consistent. However, it seemed as though demographic, psychological and interpersonal variables played a role in how children responded to parental illness. Variables that may affect children's functioning identified by this research include parental emotional distress and the presence of obvious physical symptoms in the parent. In children it was found that their perception of the seriousness of the parent's illness was related to levels of distress, but that the children's appraisal or understanding was independent of the objective characteristics of the illness.

1.2.6 Children's conceptions of HIV/AIDS

AIDS-affected children's responses to parental HIV infection is in part influenced by their understanding of their body, illness and death, which becomes increasingly sophisticated with developmental maturation. Their understandings are constructed around both environmental input and individual factors that process and make sense of what is known to the child. Studies on children's conceptions of AIDS (Armistead et al., 1999; Walsh & Bibace, 1991; Young, Schvaneveldt, Lindauer & Paul, 2001) have understood children's understanding according to a cognitive-developmental model developed by Walsh & Bibace (1991). The model is based on Piagetian stages of cognitive development where knowledge of HIV/AIDS develops in accordance with increasing abstract reasoning ability. This model raises a number of expectations regarding what can be expected from children based on their maturity. Young et al. (2001) asserts that by the age of nine children have the capacities to understand biological causes of illness and the finality of death. However, experience, exposure and culture add to knowledge bases and to understanding.

Armistead et al. (1999) and Fox et al. (2002) raise the issue of the difference between children's knowledge and understanding of HIV/AIDS. Knowledge is about the content and accuracy of information held by the child and does not refer to how this factual information is integrated into a conceptual framework. Understanding then is about the manner in which children think about and interpret information. Practically this distinction has relevance for the notion that presentation of information per se does not result in understanding (Walsh & Bibace, 1991). The manner in which a child understands parental illness may not be congruent with the objective reality of parental illness and in cases where there is insufficient parental guidance, a child's ideas about HIV may take the form of frightening fantasies and thoughts (Lewis, 1995).

1.2.7 HIV/AIDS-associated stressors

The case for the uniqueness of HIV/AIDS is consistently repeated in the literature in this area (Geballe & Gruendel, 1998; Lewis, 1995; Siegel & Gorey, 1994). Broadly, the difference resides in the type of and number of stressors AIDS-affected children may experience. The major stressor facing AIDS-affected children is the anticipated death of the HIV infected parent. The course and degree of incapacitation of the illness is often uncertain and punctuated by relative periods of health or illness. Clinical reports suggest that material and psychosocial stressors that accompany the illness of an HIV-infected parent may

complicate the process of grieving for these children. AIDS-associated stressors or challenges are identified in broad terms and include factors that may or may not be exclusively associated with HIV/AIDS or that may be exacerbated by the lack of material and emotional resources. Geballe and Gruendel (1998) and Wild (2001) have listed a number of challenges or stressors faced by children whose parents are living with HIV. These include multiple losses, stigma, disturbing and uncertain clinical course of the illness, lack of adequate care and control and economic deprivation and disrupted schooling. Material and physical deprivation is particularly salient in this population as in the USA, and, in developing countries, HIV/AIDS has had a disproportionate impact on economically deprived communities (Wilde, 2001). The impact of socio-economic conditions, anticipatory grief and stigma on the psychosocial adjustment of AIDS-affected children will be discussed in detail.

1.2.7.a Socio-economic conditions

The stressors that AIDS-affected children are exposed to vary in nature and severity from one situation to another. In Africa, the impact of poverty is such that inadequate material resources and parental care will compromise the future of these children. Research from East and Southern Africa shows that children are often required to head up households with minimal access to resources. Often children leave school to work for and take care of the HIV-infected parent and siblings (Madorin, 1999; Preble, 1998). Children affected by AIDS in South Africa and Africa are at risk for malnutrition, abandonment and exploitation (UNICEF, 1999). Perhaps the most overriding factor engendering vulnerability in AIDS-affected, orphaned and infected children in Africa is poverty, which fosters a sense of hopelessness toward the future (Madorin, 1999). A study conducted in Zimbabwe (Foster, Makufa, Drew, Mashumba, & Kambeu, 1997) showed that AIDS-orphans faced discrimination based on their orphan status or poverty rather than on parental HIV status. Similarly, in South Africa, children in the Strobe and Barrett Grant (2001) study spoke about being discriminated against at school by peers and teachers because they were unable to afford basic school necessities.

1.2.7.b Anticipatory grief

In the case of AIDS-affected children, living with an HIV positive parent brings with it the threat of death experienced as a series of unpredictable and fluctuating physical symptoms, the nature of which may be potentially life-threatening. Death is certain but the time of and

quality of death is uncertain (Geballe & Gruendel, 1998). A child may grieve in anticipation of death without a sense of finality. Pivnick and Villegas (2000) suggest that during parental illness prolonged anticipatory grief may be suffered, that is described as an isolating and painful process in response to a sense of loss before death. Studies show that adults expressed feelings of distress, depression, anger and preoccupation with thoughts of the ill person indicating a grief reaction as they anticipated death (Sweeting & Gilhooly, 1990). The anticipatory grief reaction remains a subjective experience that has never been consistently operationally defined. However, Sweeting & Gilhooly (1990) argue that anticipatory grief is a normal and expected process in coping with the anticipated death of a loved one.

Although not specifically applicable to anticipatory grief, Worden (1996) highlights a number of processes that mediate grief or children's personal thoughts, experiences and feelings associated with anticipated death. Children's comprehension of death or cause of death is a major determinant of how mourning proceeds. The influence of family processes such as the relationship with both parents is given prominence as the reactions of adults in the lives of children influence their bereavement or adaptation to loss. Parents play an important role in facilitating grief by allowing children to experience and express the emotional aspects of loss. Affective expressions are a normal part of bereavement, where sadness, anxiety, guilt and anger were most commonly seen in children (Worden, 1996).

A study conducted in the Eastern Cape on AIDS-orphans (Fox et al., 2002) showed that within the family, dying was not discussed with the children. Unable to make sense of their situation children were left with minimal understanding and emotional support or guidance. Without parental support children lost their sense of security which further exacerbated fears about their futures. Silence around death in the home maintained the children's inability to express their fears and grief that they kept to themselves. Lack of communication fostered a sense of isolation, helplessness and loss of hope in the future.

1.2.7.c HIV/AIDS-associated stigma

Stigma and discrimination against children infected with and affected by HIV/AIDS is characteristic of the HIV/AIDS epidemic in many countries (Geballe & Gruendel, 1998, Siegel & Gorey, 1994; Wild, 2001). In South Africa, the nature of this stigma is understood to arise in particular discourses about HIV (Strobe & Barrett Grant, 2001). HIV infection is

seen as a punishment for immoral behaviour such as promiscuity and infected persons are understood to be personally responsible in contracting HIV. Ignorance and lack of knowledge about transmission leads to fear and irrational behaviour that includes social distancing from infected persons so as to reduce personal risk of infection. Stigma and prejudice against HIV infected persons seems to be based on limited tolerance for those outside the 'norm'. Community members in the Strobe & Barrett Grant (2001) study communicated their disinclination to help AIDS-affected children including infected and orphaned children for fear that these children would infect them with HIV. Furthermore, community members believed that HIV-infected parents should take responsibility for caring for their own children.

Community beliefs can be understood with regard to a definition of stigma proposed by Burris (1999) quoted in Strobe & Barrett Grant (2001, p.3), in which he suggests that stigma can be understood as a social relation between a stigmatised person and 'normal' person that is based on a shared belief that an aspect of the stigmatised person is in some way "spoiled". In interactions with others stigmatised persons are attributed qualities that identify them as somehow "fundamentally and shamefully different". Those that are stigmatised often share this view of themselves as "deviant". Strobe & Barrett Grant (2001) conclude that the impact of AIDS-associated stigma is extremely damaging for children in that it increases their vulnerability as it diminishes their ability to use resources that may serve a protective function. Children in this study reported facing stigma in their immediate families and within their communities in places such as school and church. AIDS-affected children reported being marginalised, ill treated and isolated. The authors argue that behaviour towards these children revealed social attitudes of children as "shamefully different" (p.18) either due to perceived HIV status or association with HIV and AIDS.

Secrecy

The response of AIDS-affected families to stigma may be to keep their status a secret, where children may not be told about parental infection or they might be instructed to keep parental HIV-infection a secret from others. Even in cases where children are not instructed to keep a secret, societal attitudes expressed as discrimination serve to enforce children's silence. Most children and adolescents do not tell their friends about parental HIV infection and fewer than half of parents in HIV-affected families tell their children about their infection (Nagler Adnopolz & Forsyth, 1995). The content of secrets is usually defined in terms of moral

badness or because of external or internal prohibitions. The need to keep certain information from others may be associated with feelings of shame, social disapproval and moral badness (Last & Aharoni-Etzioni, 1995). Secrecy increases a sense of shame associated with HIV/AIDS and children may take this stigma as part of their own identity (Nagler et al., 1995).

Secrecy in the family

Brown-Smith (1998, p.23) defines family secret as, "any information that directly affects or concerns one but is either withheld or differentially shared between or among family members". Secrets have a certain function in families in that they preserve the family's image from information that if disclosed would be valued negatively. Furthermore keeping certain information a secret influences family relations. Secrets prescribe the content and nature of familial communication thereby affecting every relationship between secret-holder and other family members. Secrets about HIV within the family may stem from the infected parent's fear of rejection and thereby loss of the family. Parents may also be concerned with their children's responses and may wish to protect them in some way by not telling (Papp, 1993). Through silence and secrecy, the parent's shame is indirectly communicated to children. The infected parent's response to their infection may well influence their capacity to parent, which in turn impacts on their ability to engage openly with their children about HIV infection. One consequence of secrets is to make the disease unknowable and unnameable leaving children without a means with which to make sense of changes in the parent and home. In addition, children may feel left out or they may create myths or fantasies to explain what is unknown (Brown-Smith, 1998). The degree of secrecy may vary, but a reluctance to engage honestly with children's questions increases their anxiety. (Nagler et al., 1995).

Shame

The literature on shame is vast with many different conceptualisations based on specific theoretical perspectives. There is no one definition of shame, nor one unified conceptualisation (Tangney & Fischer, 1995). The functionalist approach is used to highlight and explain behaviour such as secrecy especially in light of socially constructed censure in prevailing views of HIV/AIDS in South Africa. The act of hiding from others due to moral transgression or 'badness' is often associated with feelings of shame. A functionalist conceptualisation of shame (Barrett, 1995, p.44) states that shame is associated with certain

behaviours or "action tendencies", that include withdrawal or disappearance from evaluating others. She suggests that shame involves focus on the self that one is bad and a sense that another person believes the same, although it is not necessary for the person to be physically present. This understanding views shame as a self-conscious emotion that develops in response to perceived or experienced social censure. Socialisation processes in which rules and standards are constructed serve to delineate guidelines that people follow to facilitate human interaction. Within these constructed norms an appraisal of self as bad or that someone thinks that one is bad may elicit shame.

1.2.8 Interventions

Intervention design in South Africa needs to be mindful of the "complex biological, social, political, psychological and cultural issues surrounding the problem of HIV/AIDS" in this context (Sewpaul, 2001). Chronic and pervasive poverty is a socio-economic factor that psychosocial interventions cannot overcome (Dawes & Donald, 2000). The sustainability of interventions is undermined by the lack of resources and related capacities. In response to this, interventions in South Africa have taken the form of community-based projects that make use of local resources and cultural practices in an effort to offer meaningful services.

Dawes & Donald (2000) reiterate the need for intervention initiatives to be underpinned by theory and research. They suggest a number of principles guiding intervention design in South Africa. Although community participation and sensitivity to cultural norms are emphasised, the importance of child developmental theory is underscored. In this respect interventions should be informed by knowledge of developmental domains and the challenges evident in these. Because development occurs in context, intervention should occur at multiple levels such as the school and family. Lastly, interventions should promote and build on protective factors. Madorin (1999) and Wild, (2001) underscore findings from research on stress and childhood development, as they reiterate that no one stressful factor or variable can account for children's adjustment to maternal HIV-infection. Rather the context in which this occurs may be more important predictors of children's adjustment. Thus, the identification of processes that mediate the experiences of AIDS-affected children, particularly with regard to protective processes plays a pivotal role in the development of interventions.

CHAPTER TWO-METHODOLOGY

2. Introduction

A case study method can be conceptualised as a process of inquiry into the experiences of AIDS-affected children. The principles of case study method will be discussed to clarify its use in the present study.

2.1 The case study research method

Stake (2000) proposes that case study method is more about what is to be studied than a methodological choice. A case studied is defined by an interest in that case and not only by the method of inquiry used. Bromley (1986, p.24) defines psychological case study as "any systematic account of a person in a situation provided that account is based on empirical evidence and rational methods of inference". A basic logic underlies the process of case study research, or a 'quasi-judicial' non-experimental method informs the procedures incorporated within each stage of the research process (Bromley 1986).

The strategy of inquiry used to investigate a case is chosen according to what it is that is being studied about the case and is not confined to a particular methodology (Bromley, 1986). Since this study seeks to investigate the experiences of AIDS-affected children and is concerned with the phenomenology or subjective meaning of their experiences, a qualitative approach to data collection was chosen. The use of case study as an inquiry into the children's experiences is intrinsic according to Stake's (2000) definition of case types. Intrinsic interest refers to wanting a better understanding of a particular case, a child living with an HIV positive mother, based on its own merits, whether ordinary or unusual.

An essential feature of a case, or person, is an interest in aspects of their experience that are naturally occurring events in the real world (Bromley, 1986). The case is usually studied in its context. Information about the person's life history plays a role in understanding the situational aspects of their accounts. In part, inquiry is historical rather than prospective and the data obtained is unique to the experiences of a person. According to Bromley (1986) a case study should aim to offer not only a description of a person in a situation but also an explanation about the significance of their experiences. A narrative account would include material about a person's actions, experiences, personal qualities and circumstances out of which a causal analysis attempts to explain the facts and events in the narrative. In this

fashion, Bromley (1986) asserts that a case study can be understood as a reconstructive and interpretative exercise.

The boundaries of a case (Stake, 2000) need to be specified and decisions are made as to the degree of complexity that will be investigated. Case-material is selective in that some issues within a case will be more important to an account of a person than others. Within a case, issues of interest are defined and specified by the researcher according to principles of scientific inquiry. As Bromley (1986) indicates the value of a case study rests on the degree to which the data and relationships identified can meaningfully account for the phenomena of interest and the degree to which the single case adds to ideas and conceptual frameworks in the area of interest.

Although this study is specifically interested in the idiographic accounts of children, their experiences can only be described and interpreted within relevant conceptual frameworks. Bromley (1986, p.6) refers to the "scientific character of an idiographic approach", that is derived from abstract concepts from which individual cases are made sense of. Not only does comparison of cases influence the terms of reference of the case studied but a description and explanation of the present case adds knowledge to an existing body of theory or case-law. The case-law or theory is added to and refined as individual cases of a type successively contribute to knowledge in an area of interest.

Regardless of its purpose, case study method follows the "logic of scientific method" (Bromley, 1986) or a quasi-judicial procedure in order to formulate rational and empirical argument. In general the employment of such a procedure will guide the description of relevant data, organisation of case-material, analysis of case material, critical evaluation of each aspect of the process and the formulation of inferences or arguments about the data collected.

The research process to be followed in case study method can be understood as incorporating a number of interdependent phases. Edwards (1998, p.43) describes each phase in terms of specific aims and strategies that he refers to as types of "case study work". This study is organised according to these phases as a means of presenting sequential aspects of the research process. Since issues of validity are attended to at every phase, the aims, strategies and threats to validity will be discussed as each phase is presented.

2.2 Sampling

Purposive sampling was used (Barker, Pistrang & Elliot, 2002), to recruit mother-child dyads according to the following criteria: 1) the mother-child dyads resided in Grahamstown; 2) they had a basic proficiency in English/Afrikaans; 3) the mothers were in the minor-symptomatic phase HIV infection; 4) the children were uninfected; 5) the children lived with the HIV positive mother; 6) the children were between the ages of 8-12 and 7) they had been informed of their mother's HIV status. Two mother-child dyads that fulfilled the above criteria were recruited from HIV/AIDS support centres and organisations in Grahamstown. Prior to the interviews two informal meetings were held with the mothers during which the nature of the research was explained and consent was given for their participation. An English-Xhosa interpreter was used when the mothers read and signed the consent forms written in Xhosa in order to ensure that they had complete understanding of the research in which they participated. The children signed their own consent form during their introductory interview (see section 2.3.5.b).

2.3 Data collection

2.3.1 Semi-structured Interviews

Data was collected from the mother-child dyads. Semi-structured interviews were conducted with the mothers and the children according to prepared guidelines (Barker et al., 2002). A framework was prepared to structure the interviews according to delineated areas of interest. However, particularly in the child interviews, strict adherence to the interview guide was not followed. Questioning followed a recursive process as both the mothers and children introduced aspects of their experiences not anticipated by the interview guide. Thus, the interview guide served as a reminder of the areas to be covered and as a springboard to related issues (Barker et al., 2002). The use of semi-structured interviews was chosen specifically because of the utility of this method in generating phenomenological data (Barker et al., 2002). Eliciting data on the participant's views of themselves and surrounding world was a means to gain an understanding of the children's "lived contexts" (Dawes & Donald, 2000). Such an inquiry allowed the story of a child living in a particular situation to be teased out and thereby to provide a rich and complex description of the meaning the child brought to bear on his/her unique context. This study was designed with a view to understanding the experiences of children within their own world and thereby to provide a "thick description" (Stake, 2000).

Other data

HIV/AIDS-related literature that had been read by one child was obtained from the "Soul City" offices and statistics on violent crime levels was obtained from the Grahamstown Police Services (2003).

2.3.2 Interview settings

One mother was interviewed in her work office and the other at the HIV/AIDS centre that she attended. One child was interviewed in her home and the other was interviewed at the HIV/AIDS centre attended by his mother. Permission was obtained from the centre to use office space and the crèche room to interview the mother and child, respectively.

2.3.3 Language and the use of an interpreter

Both the mothers and the children spoke Xhosa as their first language. However, the mothers felt confident in their ability to speak English and declined the use of an interpreter. One child is schooled in English and was able to communicate easily while the other had difficulty with English. An interpreter was used during the interviews with the second child. In comparison to the first child, this had an impact on the interviewing process in terms of the content of information elicited, rapport developed and around the practicalities of puppet play.

Specific preparations were made for the use of an interpreter (Swartz, 1998). Permission was obtained from the participants and introductions made prior to the interviews. The interpreter's role was defined and clarified in discussions about the details and aims of the interview process and the research in general. During the interviews, the interpreter translated speech and acted as a culture broker by explaining the child's experiences in terms of ideas and beliefs embedded within his culture (Swartz, 1998). Although, the researcher and interpreter worked as a team with open communication regarding the details of interviewing, the act of translating speech in itself introduced questions about the accuracy and thus validity of the child's account. Swartz (1998) outlines a number of challenges posed by the use of an interpreter. The interpreter in this study was not specifically trained in this regard and the limited amount of training done by the researcher would not have been sufficient to counter common errors made in the interpretation process. Thus, omission, addition, condensation and substitution of information and words may have undermined the child's account. For example, matching of words in two languages is complex as there is not

necessarily one correct choice and translation is imperfect. On a practical level, the presence of a third person in the interview altered the relationship between researcher and child, which impacted on the development of rapport and trust. Puppet play was halted and flow was interrupted, as the interpreter needed to translate concurrently with the play.

2.3.4 Interviews with the mothers

Two audiotaped interviews of 60-90 minutes each were conducted according to prepared guidelines. The semi-structured interviews covered aspects of the child and his/her family, including the child's developmental history, adjustment, personality, the mother's current concerns about the child, family composition and functioning, and the mother's perceptions of her HIV status. The second interview was conducted after the completion of the child interviews and was used to clarify topics from the first interview and from the child interviews.

Interviews with the mothers were conducted with the aim of generating contextual or background information in which the children's narratives were couched and understood. As Bromley (1986) asserts, the case should be situated in the context from which problems or issues are understood. By virtue of their role in their children's lives, the mothers were able to provide information about the children in their natural settings and they were utilised as "informants" (Barker et al., 2002). An interrogative approach (Bromley, 1986) was used during the interviews in order to operationalise metaphorical language and to clarify or make the participants' meanings explicit. In accordance with a quasi-judicial procedure, statements given by the participant are continually examined in terms of other statements or with regard to the participant's account as a whole. Identification of events, actions, circumstances and the participant's state of mind aided this task. Negotiating meaning is an important aspect of the interview process (Barker et al., 2002) but even more so when the interviewer and interviewee do not share a common language or culture. Swartz (1998) argues that language use differs across social groups and that the usage of words may offer different implications for different speech communities.

2.3.5 Interviews with the children

Five interviews were conducted with one child and four with the other. In the former case an extra interview was required to clarify and explore issues raised in the previous interviews. The duration of the interviews was 50 minutes and they were video and audio taped. The

interview set comprised an introductory interview followed by play interviews, both of which incorporated the use of play techniques to facilitate both the introduction and exploration of issues and problems salient to the children.

2.3.5.a Theory of play and play techniques

Children communicate their thoughts, feelings and view of the world through play (Schaefer & Cangelosi, 1993). In light of this, play techniques were used in the child interviews. Irwin (1993) proposes that play offers the best way whereby we can know about the psychic reality of the child and his/her worries and wishes. It is by no means a direct route to learning about what a child thinks and feels, as play is inevitably made up of myriad experiences past and present, and feelings and wishes expressed in the spirit of make believe. Conn (1993) proposes that play interviews can be used to help children contribute material about their personal, emotional and imaginative life. Techniques or tools of play such as "specific stimulus situations" (Hambridge, 1993), puppet play, drawings and feeling-colour keys were utilised in this study. Each technique is discussed in terms of its utility in facilitating the interview process.

"Specific stimulus situations" and structured play

Since the interviews in this study were time limited, the idea of using "specific stimulus situations" devised by David M. Levy (Hambridge, 1993) was incorporated into the play interviews. Hambridge (1993) discusses the use of stimulus situations through the medium of structured play therapy as a means to focus the child's attention, to stimulate activity along the point of focus and to gain information. Structured play can be used selectively to stimulate and maintain independent and creative free play. As a directive approach, structured play introduces a focus of interest that had been indicated by the child. The therapist (researcher) dramatically re-creates an event, situation or feeling that relates directly to the conflict or problem for the child. The child's participation in the introduced play is then encouraged so that he/she can show what happens. The introduction of a play 'scene' can potentially evoke anxiety or precipitate acting out behaviour in the child. Hambridge (1993) believes that this can be ameliorated if the child feels secure in his/her relationship with the therapist (researcher) and if the play scene is relevant to the child. In the play interviews, decisions about when and how to set a play scene was not predetermined but made during the play if such an opportunity arose. The specificity of the scene was

determined according to the degree of threat that a conflict or problem would pose to the child.

Puppet Play

Puppet play has a number of features that would facilitate the playing out of stimulus situations. Puppets are used by children to play out aspects of their experiences as they attribute feelings, behaviours and thoughts to the puppets in a realm removed from reality. At times children find it difficult to verbalise a distressing feeling or thought directly and it is often easier if a puppet says it for them. In this manner, the use of puppets provides distance and thereby makes it safer for children to reveal their private thoughts, fears and anxieties (Oaklander, 1988). Irwin (1993) states that because the puppet play is 'just a story' or 'just pretend' it offers a sense of psychic protection and lowers the child's defences and levels of anxiety. The stories created by children in puppet play can be interpreted along a number of dimensions, to give information about the child's defences, coping styles, preoccupations and conflicts (Irwin, 1993). During the interviews, the content and other dimensions of the children's puppet play in response to a stimulus situation, were used to ask questions around thoughts and feelings expressed by the puppets. In practice the two children responded differently to the puppets, and thus their use in the structured interviews required flexibility on the part of the researcher.

Drawings

Drawings as a familiar and non-threatening task for children were used to encourage children to share more about their experiences, to gain access to their thoughts about family members and as alternative to puppet play. Oaklander (1988) believes that what is seen in or communicated by a drawing can be understood as expressions of the child's inner world and serves to "speak" for the child. Giving drawings a title proved an effective means of eliciting additional information (Oaklander, 1988).

Feeling-colour keys

Feeling-colour keys were used to teach the children a feeling language. The keys consisted of feelings matched to colours or feeling faces. Five main feelings were introduced; sad, happy, angry, worried and afraid. These feeling-colour keys were used in two different ways, either the children filled in a 'feeling bottle' with the different feelings as colours they felt or to provide distance they attributed the feelings to an animal drawing and using colouring-in

showed how the animal was feeling (Schaefer & Cangelosi, 1993). This technique was used to tap into how the children felt about a particular issue and further provided them with a means to make their feelings known.

2.3.5.b Introductory interview and play interviews

A number of tasks were completed during the introductory interview, with the aim of orientating the children to the researcher, to the aims of the interviews and to researcher expectations. The children were encouraged to ask questions and they were asked about their expectations or concerns regarding the interviews. The researcher made it known to the children that she had also interviewed their mothers about HIV. The sentence completion test (Knell, 1993) was named the 'getting to know you' game. In this manner the children were introduced to the puppets as they were used to state and complete sentences. The feeling-colour key was shown and explained to the children. The first interview allowed the children to get to know the researcher, which facilitated the building of rapport. This time was used to introduce the children to the recording equipment, as both were curious about the audiotape and video camera.

The play interviews were counted down so that the children had a clear idea of how many meetings were left with the researcher. These were semi-structured and all the questions started out as broad enquiries using open-ended questions. Questions thereafter followed the children's lead and were posed to encourage deeper exploration of an issue or to generate more information about a particular relationship. Family questions were used as a starting point to gather information about the children's background and context. In order to facilitate this process, children were asked to draw a picture of their family, themselves and one of them and their mothers together or to play 'family' using the puppets. The play techniques were used with the aim of encouraging further description and eliciting information about familial relationships.

Since neither of the children spontaneously brought up the subject of HIV, the researcher introduced the topic by asking if they knew what HIV was. Once the topic of HIV had been broached, the researcher guided the inquiry with open-ended questions. For example, with regard to their experience of when their mothers disclosed their HIV status, the children were asked, "can you tell me about when your mom told you she had HIV?" The children's responses to open ended questions then guided further exploration, either as verbal

discussions or through the use of drawings, feeling tasks or puppet play around a stimulus situation introduced by the researcher. Questioning was recursive in that the children's responses informed further questioning.

Overcoming question avoidance

At times the children did not wish to speak about certain topics. For example, initially one child reported that she did not know about HIV at all. Avoidance was a typical response when both the children were feeling anxious and insecure. At these times, the researcher suggested that the children speak about their feelings using the feeling-colour keys and related colouring tasks. Affect labelling in this manner proved to be an effective technique overcoming avoidance in the children. As a general rule, the children's defences were respected and they were not pushed beyond what they were willing to freely disclose.

2.3.6 Validity

During data collection the validity of case material gathered rests on its genuineness and freedom of bias and selection effects (Edwards, 1998). The degree to which this can be achieved is central to the validity of subsequent phases of the research process. Bromley (1986) refers to data as evidence, the quality of which can be assessed in terms of its admissibility, relevancy, and credibility. The consistency and accuracy of the data needs to be critically examined. Assessment of data in these terms progressed continually during the interviews.

The threats to validity during this stage stem from bias and assumption introduced by the researcher and the credibility of the sources of evidence, that is mother-child dyads. In the case of the mother and child interviews, it is recognised that the interview process can be understood as producing "situated understandings grounded in specific interactional episodes" (Denzin & Lincoln, 2000, p. 633). In this regard the researcher was an active participant in the interview and would have influenced the nature and quality of the information generated. The researcher's assumptions and biases would have influenced questioning and understanding of the participant's account and her presence itself would have elicited specific discourses from the participant.

Whether the mothers or children accurately portrayed their experiences is contingent on a number of factors. Barker et al. (2002) argue that idiosyncratic, subjective data portray one

perspective or way of seeing the world that may not reflect 'reality'. Furthermore, participants may not offer truthful information due to the lack of trust, attempts to conform to perceived researcher expectations or due to attempts to portray themselves in a positive light. The participants themselves may be unaware of the motivations for their behaviour and the degree of their conscious self-knowledge may be limited. However, attempts were made to gather meaningful and valid material. In this regard, statements were examined for inconsistencies both within an interview and between mother-child interviews that were explored further. The mothers and children's meanings were made explicit so that the researcher's understanding did not rest on presumptions. Re-listening to audio-taped interviews facilitated the identification of gaps, vagueness, assumptions and missing information that was further explored in subsequent interviews. With regard to the validity of play interviews, the content of play in and of itself did not form the basis for interpretation of the children's thoughts or feelings. As much as was possible, questions attempted to elicit the child's meaning or perceptions of a particular issue. For example, when a puppet character kept his HIV status a secret, questions were asked around issues of secrecy to determine whether the child felt the same way.

Demand characteristics during interviews were minimised by the initial use of broad themes of play and open-ended questions that required the participants to offer an account salient to them. It further encouraged a certain amount of self-reflection and analysis in the absence of researcher input or interference. In this manner the participants' responses were less constrained or limited by perceived researcher expectations. The use of open-ended questions (Barker et al., 2002); continual review of the consistency of statements, attention to detail, suspension of judgement and a genuine, empathic approach on the part of the researcher (Edwards, 1998); served to encourage meaningful disclosure by the participants and to increase the validity of the material gathered.

2.4 DATA REDUCTION

The process of writing synopses of the transcribed interviews entailed undertaking a number of steps with the aim of documenting an unbiased description of the mothers' and children's accounts. However, within this choices were made about what issues to address and what to omit. Decisions of inclusion were largely based on two main principles of case-work. Firstly, pre-existing conceptual frameworks were used because descriptive work is in some respects based on theory (Edwards, 1998) and secondly on the assessment of the relevancy of the data

(Bromley, 1986). In terms of this study, two descriptive synopses were produced, namely contextual narratives and play interview narratives. These were based on detailed descriptions of the two transcribed interview types. Because the interview types had different aims, descriptive work was carried out with different foci of interest and will be discussed separately.

2.4.1 Contextual Narratives

Maternal interviews were described in terms of the background and contextual information offered. In particular, literature on the potential role of families on mediating or moderating the effects of parental chronic illness, HIV/AIDS infection and bereavement in children guided the identification of key features of the maternal interviews. For example, information around family functioning, maternal physical health, disclosure and communication around HIV/AIDS was included. The identified issues were then described and documented in detail under appropriate headings. In the contextual narratives, which were based on the detailed descriptions, key features of the maternal interviews were highlighted not only with regard to pre-existing frameworks but also in terms of the children's interviews. Statements were compared across interviews and assessed in relation to their relevance to the children's statements and the degree to which they fitted within a particular discourse. However, information was not discarded because it contradicted the children's words or because it introduced inconsistency. Rather, the contribution it made to an issue or to the internal coherence of mother-child data was important. The contextual narratives took the form of a synopsis of the mothers' experiences using their terms and meanings without interpretation.

2.4.2 Play interview narratives

The child interviews were transcribed, the content of which was then described in detail to produce lengthy unbiased documentation of the interviews. In order to reduce a lengthy document, decisions as to what information to include were made according to the quality of the data itself, that is substantive statements were chosen over digressions, vague and undeveloped or unexplored ideas. To some extent pre-existing frameworks in which the data was embedded guided the identification of salient areas. Theory on the psychosocial adjustment of AIDS-affected children guided the identification of AIDS-related issues that were introduced and spoken about the children. Related literature on protective and vulnerability factors including those usually found in families further informed a broad

reading guide. Case material in each interview was chosen according to these broad areas and was presented as a detailed synopsis of the sequential interviews. The children's terms and meanings were used without interpretation.

It is important to note that as a starting point, the data reduction phase followed a recursive pattern that extended throughout the research process. The refinement of case material was a gradual process that followed different pathways and at this stage of the research endeavour aimed to document the experiences of the participant's in their terms. Descriptive work entailed many readings of the interview transcripts, writing a detailed and lengthy description of each of the interview sets and referral to the relevant literature (Edwards, 1998). The descriptive narratives are lengthy which reflects the researcher's decision not to foreclose or narrow the available case material too early on in the research process. Choosing relevant versus irrelevant statements at this stage presupposed a limited number of interpretative options.

2.4.3 Validity

The validity of the descriptive synopses is determined by freedom from researcher imposition of assumption, bias and selection bias. However, it is important to acknowledge that despite best efforts to minimise bias the researcher ultimately decides what will be included as he/she reworks the narrative according to his/her understanding of the meanings, issues, and problems. The integrity of the data is dependent on the participant as well as researcher self-reflection (Stake, 2000).

In order to limit bias introduced by the researcher during the description phase, case material was re-read, transcribed interviews were described and documented in detail using terms employed by the participants. This increased familiarity with the material and exposed unsubstantiated data and missing information. In some instances corroborative evidence was sought. The material selected for the narratives was a product of untested researcher assumptions and theoretical frameworks brought to bear on the material. However, every effort was made to constrain interpretation of the material so that it portrayed unique experiences and meanings as expressed by the participants (Edwards, 1998).

2.5 Theoretical-heuristic work-analysis and interpretation

The contextual and play interview narratives were used for the generation of theory. A heuristic reading of the narratives was conducted with a view to grouping recurrent experiential and contextual statements, ideas and behaviours in themes. The main issues or problems were then identified. In addition the children's experiences were read in terms of their context and these two aspects of the case were integrated. The theoretical lenses or frames (Edwards, 1998) used were based on literature on stress and coping in children, AIDS-affected children, AIDS-associated stressors and protective and vulnerability factors. Research on childhood bereavement, chronic illness in families and South African based research on distressed children formed repeated readings of the synopses. Each conceptual framework provided a different but related "angle" with which to read the case material (Bromley, 1986), so as to search for patterns of meaning as they emerged from the narratives. Bromley (1986) asserts that there are two ways in which the material can be read. The content of the narratives contains both manifest and latent material. The former refers to what is read out of the text or substantive factual statements. Latent content involves an active process of giving meaning to text or reading into content. In this phase, the 'facts' contained in the narratives needed to be "spoken for" (Bromley, 1986).

The significance of the participant's experiences were explained and reworked according to abstract psychological concepts whereby the latent or deeper levels of their experience could be explicated. Inferences were made about the participant's beliefs, ideas and behaviours according to deductive reasoning (Bromley, 1986 and Barker et al., 2002). In this manner testable hypothesis are made from theories. The phenomena of AIDS-affected children was understood in terms of their experiences but at the same time their experiences were interpreted according to conceptual frameworks that illustrated aspects of their situation more fully. Arguments formulated to illustrate or convey ideas about aspects of the children's experiences needed to be supported by the case material and had to be consistent with the appropriate conceptual framework (Bromley, 1986). Well-supported interpretations that show a logical link between data and theory serve to ensure internal validity in this phase.

2.5.1 Validity

Theory that is relevant to a case plays an important role in limiting the scope of a case study as well as guiding the identification of distinctions and salient issues. Furthermore,

conceptual frameworks allow the researcher to make sense of a case in terms of other similar cases (Bromley, 1986). However, heuristic readings may undermine the internal validity of case material in two ways.

Firstly, pre-existing theoretical frameworks incorporate a number of underlying assumptions that may not be applicable to the case. As far as possible, assumptions implicit in abstract concepts should be made explicit with regard to the case (Bromley, 1986). In this study, with the exception of culturally applicable literature, most of the theory has been based on USA samples. Thus this theory is constructed and understood in terms of its historical, social and cultural roots. The applicability of these frameworks to understanding AIDS-affected children in South Africa may be limited. For example, literature on family functioning is mostly based on households headed by two parents. In addition, most of the knowledge in this field is based on quantification and multivariate statistics. These types of studies have specific aims and thus have conceptually different ways of looking at the adjustment of AIDS-affected children.

Secondly, with these conceptual frameworks in mind, a reading of the case material may be done only in terms of this knowledge. In other words only confirmatory evidence will be sought resulting in 'finding what you are looking for'. Internal validity in the interpretative stage is thus undermined by uncritical imposition of meaning on case material solely in terms of a pre-existing structures or making the data fit the theory whether it does or not. In order to enhance internal validity, alternative explanations and or theoretical frameworks are continuously sought so as to provide at minimum an understanding that best fits the case material (Bromley, 1986). Throughout this interpretative phase, tension was maintained between using theoretical frameworks as a guide or as an interpretation in itself. An independent judge and supervisory meetings provided feedback on the case narratives and on the themes identified. Researcher assumptions were exposed after which certain themes, arguments and inferences were revised.

Maintaining the integrity of the participants' accounts enhances external validity in case study method. The details and events recounted by the participants reflect real life experiences or their lived contexts. Conclusions drawn from the case can then be generalised outside that particular case (Edwards, 1998).

CHAPTER THREE-THE CASE NARRATIVES

3. The case narratives

Transcribed interviews are presented as detailed and unbiased descriptions of the participants' accounts. The material reflects idiographic experiences of the participants presented in their terms without interpretation. The interviews with the mothers are organised according to salient individual and family processes to form the contextual narratives. The play interview narratives are presented in terms of sequential interviews. This shows the interview process during which the children were able to gradually speak about their concerns as trust developed between researcher and child.

3.1 Contextual narrative: Funeka and Thandi

3.1.1 FAMILY BACKGROUND

Family composition and residence

Thandi aged 10 lived with her HIV positive mother Funeka, aged 38, who is employed by NAPWA (National Association of People Living with HIV/AIDS); her sister aged 16 who is at school. At the time of the interviews, two of Thandi's cousins were living with the family, they are both younger than 10 years. Thandi's father aged 55, is unemployed, deaf and receives a disability grant. His HIV status is unknown and he has been in prison since March 2002. The family lives in a one-roomed RDP house that does not have electricity, in a peri-urban area surrounding Grahamstown. Funeka owns this house.

Maternal HIV history and health

Funeka was first diagnosed with HIV in 1993 when she gave birth to Thandi. She did not receive pre or post test counselling as she believed that not much was known about HIV in 1993. She contracted HIV from a boyfriend prior to her marriage. Thandi was tested negative for HIV in 1999. In the same year, Funeka disclosed to her family and publicly. She denied experiencing HIV/AIDS related stigma. She has been receiving anti-retroviral drugs since 1999 due to her participation in a government sponsored research project on the effectiveness of anti-retroviral drugs. Her work as the "Face of AIDS" for NAPWA ensures that she is a well known figure in her community as an AIDS educator, counsellor and facilitator of HIV/AIDS support groups. At times, Funeka finds her work stressful and she attributed symptoms such as a swollen cheek to talking a great deal.

Despite admitting that she was worried about her fluctuating CD4 count and problems with a swollen gland and failing eyesight, Funeka maintained that she was healthy,

"I feel strong. I am strong".

Across the two interviews, Funeka referred to her need "for rest" four times and that she was tired. CD4 refers to the T helper cells of the human immune system that are destroyed by the HI virus. Falling CD4 levels in the body are indicative of a weakening immune system (van Dyk, 2001).

3.1.2 FAMILY FUNCTIONING

Funeka's view of Thandi and their relationship

Funeka described Thandi positively as an obedient child, who is always happy, has many friends and "sings all the time". She denied that Thandi was ever sad or angry.

According to Funeka, Thandi senses her mother's mood and asks her about her tiredness or sadness. Funeka replies by telling Thandi that she has "stress" and does not wish to talk about it with her. Thandi accommodates her mother's needs by either leaving her to sleep when Funeka tells her that she "needs to rest" or by making her tea to help her feel better.

Funeka claimed that Thandi does not tell her about her feelings, nor was Funeka aware of whether Thandi had told her friends about her HIV status or if she had experienced AIDS-related discrimination such as teasing from her friends. Funeka did not think that Thandi's behaviour has changed in any way since she disclosed her status to her.

Parental expectations

Funeka expects Thandi to help with household chores such as washing dishes, sweeping and to wash her school socks when she comes back from school. Funeka required that Thandi be at home before 5pm, to be present for supper at 6pm and to wash before she goes to bed. Funeka felt that Thandi was compliant with all these rules. Funeka does not physically punish Thandi, if she is angry with Thandi she just needs to tell her or "she can see from my face". Usually Thandi responds to her mother's anger by making her tea.

Family conflict

Funeka did not report any HIV-related conflict in the family since they had accepted her status and continue to offer practical and emotional support and love. However, from Funeka's descriptions significant conflict exists in her relationship with her husband due to

his alcohol use and related domestic violence. Her husband is currently in jail on charges of rape. Although Thandi spoke openly about her father's alcohol use, she did not mention domestic violence or his imprisonment. Funeka claimed that she visits her husband in jail every weekend and takes Thandi with her sometimes. She has told Thandi that the charges against her father are incorrect.

Financial concerns

Funeka supports the family on a monthly income of R1 200 that is made up of her disability grant for HIV and a small income from her job. Funeka was concerned about her financial difficulties and referred to this as a,

"big stress, really". Sometimes food is a problem, but I can solve for that, but not all the time".

She mentioned not being able to pay for school fees and uniforms, her disappointment that she could not send her children to better schools and her concern over her daughter's future financial security. Furthermore, Funeka's work contract was coming to an end and she was worried about finding another job.

3.1.3 FAMILY COMMUNICATION AROUND HIV/AIDS

Disclosure

Funeka had difficulty remembering when she had disclosed to Thandi. In the first interview she thought that it had been when Thandi was six years old. In the second interview she changed this and thought it must have been when Thandi was eight. Funeka wanted to disclose her status to her children because she expected them to support and nurse her when she becomes ill. She did not understand why disclosure should be an issue, since Funeka believed that it was the only decision an HIV positive parent could make.

When Funeka disclosed her status to Thandi, she gave her literature on HIV/AIDS to read. This included a book based on the Soul City television series and HIV/AIDS pamphlets. The Soul City booklet (1996) is aimed at adult or adolescent readers. Funeka said that she did not explain the books she merely gave them to her children to read. She could not remember the content of these pamphlets and books, just that they spoke about the difference between HIV and AIDS.

Family discussions

Funeka initially assured the researcher that Thandi asked her questions about HIV and that these were discussed in the family. However, during the second interview she gave a different account. She acknowledged that she could not remember the last time that she had spoken to Thandi about HIV/AIDS or her HIV status. Funeka has never sat down with Thandi since her initial disclosure. She was also unsure as to what Thandi actually knows about HIV.

Thandi had told Funeka that, "AIDS is sleeping, you are not sleeping now, you have HIV only" and that she knew not to touch other people's blood. Funeka was satisfied that this knowledge was sufficient. She had not educated Thandi on the sexual transmission of HIV as she believed that Thandi was too young for sex education and she was waiting to tell her when she turned thirteen. Funeka further admitted that she does not talk about HIV very often and if she does she tries to keep the discussion light-hearted. In contrast to the first interview, Funeka said that Thandi does not ask her questions about HIV ("she is quiet") and she doesn't always listen preferring to go outside to play.

Thandi has asked her mother, "when you die what is going to happen to me?" Funeka cried as she recalled this and admitted that she is very worried about who will support her children when she dies. She responded to Thandi's question by saying, "I will stay longer, I will be here for longer, I am not dying now". Funeka believed that Thandi was "happy" with this response.

3.2 Play interview narrative: Thandi

3.2.1 INTERVIEW ONE

Family stories

Thandi drew a genogram of her family. She included her mother, her older sister, her father and herself. Thandi responded to the researcher's request to tell her about her family by stating that "I love my family, they love me too". This was immediately followed by a description of what happens when she does something wrong,

"and then when my mother..., when I do something wrong and then my mother is cross and then I come quickly at home and then I make tea for her, she love tea! And then she is not angry with me".

Exploring "doing something wrong"

What does Thandi 'do wrong'? Her immediate response was "ummm.I don't know". However, she told the researcher that her mother would be angry with her when she played outside or if she dirtied the house while playing inside.

Thandi spoke about how her mother "beats" her if she is cross with her and her response is to go inside the house and,

"cry, if it is bad, and when she said me I must make her tea, I go. Yes."

In contrast Thandi would not admit to feeling cross with her mother ("not so much"). Thandi told another story about making tea for her mother. In this story Thandi feels cross when her mother asks her to make tea for her and she refuses to make the tea. When she does eventually make the tea, her mother no longer wants it and refuses the tea that Thandi has made for her. Thandi feels cross about this too.

Father's use of alcohol

Thandi spoke about how she had been angry with her father because of his inebriated state. She described how she had felt embarrassed by his behaviour. Thandi introduced and later readily admitted that her father drinks and gets drunk. She spoke about feeling concerned that he will hurt himself while in this condition,

"when he is drunk, maybe four or five drunk (four or five beers) then he is weak.....and he fell down".

Sentence Completion Test

Obedience to mother

Her response to the sentence 'outside I play with' produced the following reply,

" I stay at home. I sleep, when my mom said I must go to the shop, I go! When she say I must go and buy milk I go and then I come back. That's all."

Sadness

Thandi feels saddest when her mother beats her.

Fears and Nightmares

Thandi was scared of touching blood. Thandi has nightmares of robbers coming into the house to stab her. She explained that after a nightmare she calls her mother who turns on the radio so that Thandi can listen to songs that she loves. Once she and her mother have prayed she is able to sleep again.

Not talking about HIV

The researcher asked Thandi to draw a picture of HIV to show how she thought HIV would look like. Thandi said that HIV would look sad. She then drew a picture of a woman's face and upper body. The woman was smiling.

Researcher: What is the picture of?

Thandi: It shows happy, some people are happy with HIV.

3.2.2 INTERVIEW TWO

Family Stories

Thandi chose dolls to make up her family. The researcher asked Thandi to use the dolls and show something great that happened in her family once. The story that followed was about arguments between the family members over refusal to obey instructions. The play portrayed conflict between the siblings, with Thandi issuing instruction to her cousin causing the cousin to cry. The elder sister intervenes and hits Thandi. The father becomes involved and an argument between him and the elder sister ensues. Argument takes the form of shouting, hitting and running away. Thandi refuses her mother's instruction to make her tea. Later she attempts to make reparation but her mother rejects this effort.

Family rules

The researcher sets up a play scene by issuing the following guidelines: "the mom of the family comes home to tell the children something important". Thandi described how her mother tells her that she mustn't fight with her sister or father or little sister because if she does her father will hit her and she will cry. Her father will also send her to cry outside so that she does not disturb him with her noise. She further described how her father and sister say that she is naughty. When they say this she goes outside and plays with her friends.

More family stories

Thandi uses the puppets to tell another story about her family that is about conflict between the older sister and the parents. In this story Thandi is good and is rewarded and the older sister is bad and she is punished. She gives her parents traditional roles in that the mother is busy cleaning and cooking while the father is working in the garden. Instruction from the parents plays a central role in the conflict played out between the family members. Disobedience is punished by threats of physical discipline and adherence is rewarded by

acceptance and feeding. Food is withheld from the disobedient child and provided in abundance to the obedient child.

Disclosure: Funeka tells Thandi about her HIV status

There is a long silence and then Thandi whispers to the researcher,

"she tells that she is HIV and that she working with ummm NAPWA".

Thandi reported how her mother spoke about HIV and AIDS and that she talked about "everything". When her mother had finished talking she gave Thandi a book to read called "Soul City". Thandi explained that she read the book, took it to school and afterwards she understood when,

" my mother say that she go to support group. I know what support group means, the HIV people and AIDS support group".

Exploring support group

Thandi spoke about what she thought people do at the support group. She explained that they talk about themselves and "what they have inside of themselves and...everything". Thandi was unable to explain what it was that they had "inside of themselves" and instead reported that the people at the support group are happy and that they,

"tell themselves that they are healthy".

She continued to explain that some people are HIV (positive) and some have AIDS and that anyone in the support group who had HIV can have AIDS tomorrow. These people will go to the hospital and die. Some people die but not everyone.

Exploring the book 'Soul City'

Thandi told the researcher about the book. She started the story with George, the central character who was weak. George's mouth was "green and red" and his wife reacted by saying "Aiiee!" She and George went to the doctor. The doctor told George that he has AIDS and a nurse tells George's wife that she is infected with HIV. George told his friend that he and his wife have HIV. The friend is scared and they all go and get drunk. George is angry with his wife and he told her that "his wife was walking with another boy but she didn't". George went to work, he picked up something heavy, he was weak and fell down. He went to hospital and he died.

Thandi continued by saying the George didn't want his wife to tell anyone that she is HIV positive, but she told the doctor who was cross with her. The nurse was cross too. In response to the researcher Thandi explained that the doctor and nurse were angry because they did not want George's wife to have HIV. George's wife told her friend but at the same time, "she didn't want to tell anyone else she is HIV" also, "her husband said that she must not tell anyone else that her husband is HIV."

Thandi does not tell

Thandi said that she had not told any of her friends that her mother was HIV positive because if she did they would tell everyone else,

"if you tell they are going to tell another one and then its gonna be bigger and bigger and bigger".

She believed that if everyone knew they would tease her,

"..if they say can you give me your crayons and I said no..they gonna say, na, na, na, your mother is HIV, na, na, na, na. That's why I don't want to tell them. I felt cross."

Feelings

The researcher asked Thandi if she remembered how she felt the day her mother disclosed to her. Thandi whispered, "yes". Thandi coloured in blue that expressed the sadness she felt when her mother disclosed her HIV status. She said that she is going to feel sad if her mother talks to her about HIV everyday because,

" I don't want to know everything about HIV/AIDS".

Thandi also coloured in red that expressed her cross feelings. She explained that she would be cross when a friend tells her about HIV because she doesn't want to know everything. Black colouring-in signified Thandi's worried feelings. Thandi told a story about an abandoned HIV positive baby who was beaten and not fed by his/her parents. The baby had to eat dirty things from the rubbish bins. She repeated that this worried her.

3.2.3 INTERVIEW THREE

Thandi likes herself

Thandi drew a picture of herself and titled her picture " this is Thandi and I like myself." Thandi liked herself because she was obedient to her teachers and school principal. When instructed to carry out certain tasks she does so. Thandi compared herself favourably with

the other children who were not asked to go on messages because they would just go home instead (play truant).

Thandi at school

Thandi spoke at length about her experiences at school, particularly about children that disobeyed the teachers. She described how boys at her school had tattoos like prison gangs. Thandi admitted that she was scared of these boys because they were naughty and smoked cigarettes. She runs away to the office when they approach her. She described how these boys vandalise the classroom in the absence of the teachers. She believed that ghosts haunt the girl's toilets, as her school had previously been a hospital. She described how a girl had been killed in the toilets but the people that had attacked her disappeared.

Exploring helping others

Thandi likes helping her mother. She does so by helping her with housework on Saturday mornings where she sweeps the floor, washes dishes, clothing and windows. After which she eats breakfast and plays. Thandi said that it was not difficult for her to help her mother because her mother said that it is wrong not to help,

" my mother don't like that if you wake up and eat and eat and then you go play- that is wrong! You wake up make your bed and then you eat porridge and then you clean and then you eat breakfast and then you go and play".

Thandi and her mother

Thandi drew a picture of her mother. She gave the picture a title as follows:

" This is Funeka and she like money".

Thandi described the picture as her mother carrying a bag of flour on her head and carrying a shopping bag filled with yoghurt, apples, cream buns and bananas. Her mother is bringing her food. Thandi drew a picture of her and her mother together. This is what she said of her drawing: "me and my mom. We live together and we love each other and my mother love me and me love her and my mother.....silence". Thandi said that her mother likes to give her money and lunch. Thandi spoke about when she does something wrong and her mother's response,

"and when I do something wrong and she say no, she said I must hear no, and then I hear no and I stop that thing I was making wrong. That is it".

Thandi worries about her mother

Thandi explained that she worries about her mother when she comes home late (after 9pm/ when it is dark). She worried that her mother would be shot or hit. Thandi was worried that the taxi driver would kill her mother, that other people ("those coloureds in the street") would rape her and that the taxi driver whom she referred to as a "killer" would kidnap and murder her mother. She has told her mother this but Thandi believed that her mother doesn't care. She coloured the following feelings:

Blue for sad. Thandi feels sad because it could happen and maybe her mother will die- "maybe she is gonna be dead". Black for worried, because when her mother comes home late there are "coloureds in the street, they are naughty, they hit people and rape". Red for cross, " because when my mother says that she don't care".

Dying

Thandi explained that at times her mother would be tired. She is tired of washing and walking because she walks too much. Thandi believed that her mother worked as a nurse and gave sick people treatment. Thandi admitted that her mother "ate treatment", for her sickness. When Thandi was asked to tell more about her mother's illness she responded by talking about dying. Thandi reported that her mother had said that she was not ready to die yet. First she wanted to extend the house and she wanted the house to be clean. Thandi believed her mother on this ("I think that is true, it's gonna be when she dies"). Thandi reported that her mother had instructed her daughters to burn her notes and letters when she dies.

Thandi told the researcher that her mother has problems with her spectacles and a growth under her eye and will be going to hospital overnight at the end of March. Thandi was worried that she might die in hospital ("I think that she must not be dead").

Plans for the future

Thandi knew that after her mother's death she would be staying with her "other older sister" (mother's youngest sister) in Port Elizabeth.

3.2.4 INTERVIEW FOUR

Talking about HIV

Thandi denied HIV/AIDS education at school, she reported that she had not told any of her friends about her mother's status, not at school or at church. She only spoke to her mother

about HIV and even only at her mother's initiation. Thandi said that she never asks questions of her mother. Thandi stated that she could not remember what her mother had told her about HIV/AIDS. She agreed to draw a picture of HIV, of how she thought HIV looked like. Thandi drew a picture of a man in red. She gave the drawing a title: "this man is HIV positive and he do not like it".

Thandi describes the HIV man

Thandi described the man as crosss (she emphasised this word) because he does not like being HIV positive. The man is also cross when he hears that other people are HIV positive and because his wife is also HIV. Thandi said that she did not know how the man got HIV. Thandi believed that when people got HIV they don't tell anyone. However, they can tell their parents or spouse (wife) and one friend.

Researcher: What happens when people get HIV?

Thandi: They don't tell anyone

Researcher: mmm

Thandi: and they tell their parents or wife and her friends. Only.

People don't tell about their status because they will tell other people and eventually everybody will know.

Spider and Lion puppet play

The researcher gave instructions for a puppet play, that is Thandi should pretend that the spider is HIV positive. Thandi chose to call the lion HIV negative. Thandi played the part of the spider and doctor, the researcher played the role of the lion. Spider told Lion that she is HIV positive and that he is the only person she has told. The lion must promise not to tell anyone else. The lion duly promises. Spider is on the way to the doctor to check her status. She does not believe that she is HIV positive,

"because I am NOT HIV! I don't know if that is true, I am gonna go to the doctor and tell her that she must check".

Spider accepts help from Lion and asked him to accompany her to the doctor. Thandi puts on the doctor puppet and acted her role. Thandi described how the doctor put a needle in Spider's arm. Spider complained that the needle hurt. The doctor confirmed that Spider is HIV positive. Spider reacted angrily and said,

"no, I am NOT HIV positive! No!"

Spider and Lion went to Lion's house, they made tea and Spider ran to bed and cried. Spider cried because she did not want to have HIV.

Other people's responses to HIV infected persons

According to Thandi the man in the picture will take a knife and stab himself if everybody knows. She believed suicide was an option if others knew about the status of HIV infected people. Furthermore, if people know then maybe they will no longer love the HIV infected person and they will mock/tease him,

" they are gonna be naughty to him because they are gonna say...you are HIV positive, you are HIV positive."

Thandi denied that people had been naughty to her because of her mother's HIV status and she didn't believe they mocked her mother either.

The mommy and girl puppet play

Thandi chose to be the mother puppet and the researcher played the role of the daughter by following Thandi's instructions. The mother informed the daughter that she is HIV positive and asked her to make tea. She then asked the daughter to go buy bread. They then went to the doctor together to fetch tablets for the mother. They returned home. The mother was tired and told the daughter to sweep the house and wash dishes. The mother went to sleep.

Puppet play: What do little girls do when their mommies are HIV positive?

Thandi said that little girls whose mommies are HIV positive are sad. The researcher asked Thandi to tell her about this using the puppets. Thandi chose a friend doll and a little girl doll, she played with both puppets. The little girl confided in a friend about her mother's HIV status that is referred to as a big problem. The friend noticed and asked the little girl about her sadness. They play. The little girl goes to her mother, made her tea and slept with her. The friend told her mother that she was worried about the little girl. Both girl puppets prayed with their mothers. They prayed and said,

" oh, God, the mother she must not be dead and give her the power to be right".

The little girl told her mother that she was worried about her and the mother responded by saying, "oh, don't worry about me, I am gonna be right".

Thandi whispered that she would also like to tell a friend like the girl in the story. She explained that the little girl in the story felt sad and worried like she felt, but that it was nice for her to tell her friend. Thandi said that she could only tell her family.

3.2.5 INTERVIEW FIVE

The researcher invited Thandi to play with the puppets and to make up any story that she wanted. Thandi produced a complex puppet play incorporating themes of environmental threats (robbers and car accident) that cause the death of a daughter character and friend character. The mother character mourned the loss of the daughter and friend and a funeral was held for them. Their deaths are mourned-people cry and scream. Revenge is exacted on the robbers by a 'main character' that does not die and the person who caused the car accident was sent to jail. The mother died from AIDS but no funeral was held for her.

Death

Thandi spoke of the dead characters thus,

"she is gone now, she is not here anymore in the world, those two. Not here in the world."

The researcher interrupted the puppet play to ask Thandi where the dead people are. Thandi pointed upwards and said, "up". The researcher asked her where that was. Thandi said that they were with Jesus. She continued her story.

Puppet play reflecting real-life experiences and fears

After the puppet play, Thandi spontaneously remembered that she had witnessed a car accident outside her school in which a school girl had been knocked over by a car and had died. We talked about her memory. Images of blood and large crowds of people dominate her recollections. Thandi said that although her mother had spoken about the accident with her she did not wish to talk about it then,

"I didn't talk about it because I am scared of that accident".

Thandi spoke about her fear of robbers and boys, because "they love to hit each other or go and beat. I'm scared of the beating and when they have a knife in their hands and they hurt with a knife. I'm scared of that". Thandi tells of a stabbing that she had witnessed near her home. Images of blood dominated her recollection.

Exploring mother dying of AIDS

Thandi explained how the mother character got AIDS. She described how the mother got AIDS because she cried and if you cry a lot then your legs get thin. All the water in the legs comes out and the legs get thin. Thandi explained that if some-one has an open sore on their hand and if you touch that sore, something goes into your skin and from there into your blood. The blood doesn't like that thing from the sore and then you will have AIDS.

Beliefs about HIV transmission

She also said, "AIDS is trouble. Other people are scared of AIDS." The researcher asked for an explanation. Thandi spoke about AIDS in terms of a couple, where either the husband or wife is infected or both are. They check with the doctor who confirms their status and "they don't like that". The couple is unhappy with their HIV status and they run away because they have AIDS. The husband or wife have to run away if their spouse is HIV positive because they "are scared of AIDS". Thandi spoke about the fear of getting AIDS and explained that HIV is transmitted through saliva and dried blood. If the wife spits into her food and the husband eats the food he could get HIV from his wife's spit. If the wife has dried blood on her jersey and someone wears that jersey they could get HIV from the dried blood. Thandi said that she knew all of this because her mother told her and "other things I think in my brain".

Things Thandi thinks in her brain

When the researcher asked Thandi to tell her about things that she thinks in her brain, Thandi shared concerns that were not HIV related. She knew not to run in the street in case a car knocks her down. She knew it was important that she is not naughty at school, that she must not hit, kick or punch other children because she doesn't want them to do that to her and she might be expelled from school.

What can be done to help Thandi?

Thandi made suggestions as to how her mother could be helped. Her mother needed to stay HIV as opposed to getting AIDS. People needed to help her mother by giving her lifts on rainy days. Thandi needed people to protect her from people that hit her or from beggars who harass her for money in town.

3.3 Contextual narrative: Zinzi and Ondela

3.3.1 FAMILY BACKGROUND

Family composition and residence

At the time of the interviews, Ondela aged 12 lived with his HIV positive mother, Zinzi, aged 30, who has been employed as a lay counsellor at a HIV/AIDS centre since March 2002; his maternal grandmother a pensioner; his maternal uncle, aged 23 who is unemployed and his four year old half sister. Both children are not infected with HIV. The family live in a three-roomed house in a peri-urban surrounding Grahamstown.

Maternal HIV history and health

Zinzi was first diagnosed with HIV in January 2003 after a three month illness. Zinzi contracted HIV from the father of her daughter. Zinzi reported her feelings when she was first diagnosed,

" It was very painful and I thought I was going to die now. And I was very lonely, angry..." Zinzi explained that she was angry with herself, she blamed herself for getting infected.

Zinzi described her present feelings,

"I feel okay, because I accepted that, so I know that I am HIV positive and I do the right things to protect me from getting ill...."

Zinzi disclosed her status to her mother immediately. They both decided to tell the rest of the family a month later. After initial shock reactions, the family responded positively. Zinzi reported that the family was supportive in that they comfort her and encourage her to remain positive. Practically they help her with housework, her brother fetches Ondela from school and her cousin accompanies her to HIV/AIDS support groups. Zinzi reported incidents of AIDS-related stigma in her church, local clinic, from a neighbour and she has lost a number of friends. The loss of her friends was particularly painful for her,

" so I thought that that one they don't love me so I left them. I am not friends with them, they don't understand". "It was very painful, I feel lonely, lonely.....".

In October 2002, Zinzi and her four-year old daughter started treatment for tuberculosis. Zinzi complained of weakness, recurrent pins and needles in the soles of her feet and generalised tiredness,

"Sometimes I wake up feeling tired, like I must go back to bed, my legs...and I feel that I uh...I must not walk, my feet, they must give me a wheelchair or something to walk. My brain is tired, I don't want to talk. I stay home these days."

Zinzi takes multivitamins and prophylactic anti-biotics supplied by the local primary health care clinic. In addition she tries to eat "healthy food" such as fruit and vegetables daily.

3.3.2 FAMILY FUNCTIONING

Zinzi's view of her relationship with Ondela

Zinzi left Ondela solely in the care of his maternal grandmother from the age of two until six. She was away completing her schooling and was available only during school holidays. Ondela calls his grandmother 'mama' and his mother 'makazi' (aunt). Both Zinzi and her mother make decisions about Ondela's upbringing.

Zinzi described Ondela as "quiet" but also as fun loving in that he likes to laugh and make jokes. She spoke at length about his sporting ability and the trophies he had won and soccer tournaments he had attended. She was concerned about his difficulty with reading and writing at school. Despite having meetings with his teachers and attempts at tutoring him herself, this remained a concern.

Zinzi gave two differing accounts of her relationship with Ondela. In the first interview she described how they had a close relationship. Zinzi would confide in Ondela,

"We used to share everything, even if I was worried I would just call him, and maybe he started to see me first and he would say, makazi (aunt) what is wrong with you and so I just let it out".

Zinzi reported that Ondela was usually the first in the family to notice if she was unwell and he would help his mother by rubbing ointment on her legs or he would put a blanket on her and tell her to go sleep. She noticed that Ondela would stay close to her when she felt particularly ill. However, Ondela does not speak to his mother about his feelings. Zinzi felt that Ondela was vigilant about her behaviour, for example he would ask his mother why she wasn't eating vegetables if there were none on her plate and he would tell her to stop drinking alcohol ("so he say, makazi, don't drink too much because alcohol kills"). Zinzi has abstained from alcohol since December 2002.

In the second interview she gave a different account,

"when you sit with him and talk he doesn't talk much, if he has something inside he didn't want to talk with you, he rather talk with his grandmother. I think he is more comfortable with his grandmother, since he was little. It is okay with me."

Parental expectations

Zinzi expects Ondela to be home before 8pm and to attend church with the family. He does not attend church in favour of soccer practice. She would like Ondela to learn respect, be educated, to build himself a home or "whatever to make his future bright".

Family conflict

Zinzi reported that she has the most conflict with her mother over a number of topics. They argue over financial matters, principally Zinzi's ability to manage her money; they have argued over Zinzi's HIV status because initially her mother blamed her for contracting HIV and over her mother's reluctance to attend HIV/AIDS support groups with her as she feared being associated with HIV/AIDS. Ondela has overheard these arguments. Zinzi did not know what Ondela's response to these arguments is.

Financial concerns

Zinzi is dependent on welfare to support herself and her two children. She receives a disability grant for HIV/AIDS and a child support grant for her daughter. She earns a small monthly salary as a lay counsellor. Zinzi has managed to set aside R1000 in a fixed deposit for each of her children.

3.3.3 FAMILY COMMUNICATION ABOUT HIV/AIDS

Disclosure

The grandmother told Ondela, aged 10 at the time, about her daughter's HIV status with Zinzi sitting nearby. As Zinzi recalls the following was said,

"I want you to see that your mother is ill now, you know about this disease outside? He said yes. Then my mother said that Zinzi has got that disease now, so you must treat her with care and you must love her the way you love her before. And then Ondela said it is ok I understand".

Zinzi was noticeably ill at the time and it was hoped that the disclosure would pre-empt possible questions that Ondela might have had. Zinzi preferred that her mother disclose to Ondela,

"because I didn't want him to come to me at that time to ask because I was thinking that it might hurt him to tell him. So I decided that my mother must tell him".

Ondela's response to disclosure

Zinzi referred to changes in Ondela's behaviour as the "first, normal Ondela" and the "second Ondela". Soon after disclosure, Zinzi noticed that Ondela was very sad, he did not play with his friends and stayed home to watch television. This behaviour lasted two weeks. Recently, Zinzi complained that Ondela had become increasingly "cheeky". He has stayed overnight at a friend's house without asking permission and in response to his mother's requests he has said, "no, I will never do that."

Family discussions

Ondela does not engage in conversation about his mother's HIV status. Zinzi believed that Ondela did not wish to talk to her,

"it's hard but I tried sometimes, but Ondela didn't want to sit with me for a long time because he thinks that I am going to talk about this (HIV)".

Ondela has refused to accompany his mother to HIV/AIDS support groups when children are invited to attend. Zinzi has not discussed the possibility of her death with Ondela and she does not know what his thoughts are about this. Zinzi knows that Ondela receives HIV/AIDS related education at school. Besides his knowledge about transmission through blood, Zinzi was not sure about Ondela's knowledge of HIV/AIDS. She thought that he knew that kissing and hugging could not infect him. She was not sure whether he knew that HIV could be sexually transmitted,

"I think so, I didn't ask but in my mind I know that he knows or..."

3.4 PLAY INTERVIEW NARRATIVE: Ondela

Ondela was never comfortable with puppet play, though he was able to gradually play out scenes using animal characters. This may be a feature of his anxious presentation. He was rarely spontaneous and would not offer any information beyond a short answer to the questions. Ondela seemed very anxious during all the interviews and it may be that the subject matter and his anxiety around HIV/AIDS hampered his ability to engage playfully and creatively. His behaviour outside of the interview was different. Ondela always greeted the researcher enthusiastically in English and attempted to practice talking to her in this language. His behaviour outside the interview was friendly. In contrast his behaviour during the interview was subdued and withdrawn.

3.4.1 INTERVIEW ONE

Sentence completion

Relationship with his mother

Sentences about his mother provide some idea of their relationship. His mother is nice when she is not drunk. This was the second reference to his mother's drinking. Earlier Ondela had wished that his mother would stop drinking. His mother gets angry with him when he takes things without asking. She usually hits him, Ondela cries and feels sad when he is disciplined in this way.

Ondela's biggest problem

Ondela mentioned that his biggest problem was that he could not read. He also said that if he were bigger he would fight back, but he did not wish to say whom he wishes to fight.

Family composition

Ondela drew his family. In the first drawing he only included his maternal uncle. The researcher had to ask who else was in his family. Ondela named his uncle (bhuti), mama, himself, granny and little sister. In his second family drawing, Ondela left himself out and explained that there was insufficient space on the paper to include himself.

Ondela describes his family

Ondela spoke of his family members in terms of what they do. Ondela did not respond to questions such as, 'what kind of lady is she?' He was silent in response to questions about what things he told his mother and maternal grandmother.

Makhulu, his grandmother sells fish, clothing, meat and bananas in the location. She does cooking and housework. She likes cooking and she doesn't like washing dishes. She tells Ondela that he must not drink.

3.4.2 INTERVIEW TWO

Bhuti is his uncle with whom likes to clean the yard. Bhuti does not work he just "sits". Ondela likes to talk to bhuti and they talk about cricket. His little sister is four years old, at creche and Ondela likes to play chase with her. In response to the question, 'tell me about your mother', Ondela said that he has nothing to say. He only offered information in

response to specific questions. His mother likes to work in the house and she sweeps. She does not like to wash dishes.

Ondela said that his family likes to help each other clean the house. They don't do any other activities together as a family. There is nothing he doesn't like doing with his family. There was nothing that Ondela wanted to tell about his family.

Ondela's friends

Ondela has one best friend. They play together nicely not like the other boys who hit each other and quarrel with each other. Ondela and his friend "play right, there is no quarrel between us". Ondela denied fighting with the other boys and said that if they start with him he tells the teacher.

Ondela and his mother

Ondela calls his maternal grandmother 'mama' and he calls his mother 'makazi' (aunt). Ondela drew a picture of him and his mother together. Ondela was playing soccer and his mother was calling him. She wanted him to go to the shop to buy bread. When Ondela returned from the shop he resumed playing soccer. Ondela said that he liked going to church with his mother. They did not spend much time together talking. Ondela explained that he and his mother do not talk, she only talks to him when she asks him to do something for her.

Learning about HIV at school

Ondela said that his teachers at school do talk to the learners about HIV. He knows that HIV can be spread; that if some-one is bleeding and they are HIV positive he can't help them if he has a wound on his hand even if he wants to. He thought that this is how HIV gets from one person to another. The teachers told the learners that they must not go to strangers because they will infect them (interview three). He did not respond to the researcher when asked if he knew anything else. Ondela usually kept silent if he did not wish to answer questions.

Talking about HIV

Ondela said that he did not talk to anyone about HIV even though he did want to ask questions about it.

Researcher: If you need to speak about HIV or ask questions, who do you speak to?

Ondela: I don't go to anyone

Researcher: Do you ever want to talk about HIV?

Ondela: Yes

Researcher: What kind of things would you like to talk about?

Ondela: silence.

Ondela believed that HIV is painful. To have HIV is painful, he knows this because his mother told him so. He doesn't know what his mother has got but he knows that she is sick. Ondela reported that it is sad for him that his mother has HIV and "I was painful at the time she began HIV" (when she disclosed).

Feelings about disclosure

Ondela filled the feeling bottle with the feelings he had when his mother first told him. Ondela said that he remembered when this happen. Ondela filled the entire bottle with the colour black that signified worried feelings. Ondela was not willing to explore his worried feelings.

Researcher: What are you worried might happen?

Ondela: Nothing

Researcher: What happens to people who have HIV?

Ondela: Nothing

Researcher: What happens to children whose mummies have HIV?

Ondela: Nothing

3.4.3 INTERVIEW THREE

While waiting to start the interview, Ondela began playing with the crocodile puppet. The researcher decided to use this puppet in play to further encourage some free play and story telling. Ondela played out a story using the crocodile character and named him Jojo.

The crocodile is HIV positive

The researcher introduced a story line. She asked Ondela to pretend that the crocodile is HIV positive. Ondela is unwilling to describe how the crocodile feels about being HIV positive, instead he says that the crocodile is thinking about wanting to bite and eat people. The crocodile then eats Sipho the dog. The researcher introduced a new character, the lion, king of all the animals. The lion knows everything and he is not scared of the crocodile.

The lion asks Jojo about his HIV status. Jojo tells the lion that HIV will infect all the animals, he is not sure how this will happen, though. Jojo knows that HIV is an infectious disease and all you can do about it is take treatment. Jojo doesn't know where he got HIV from but he takes pills for it. Lion offers his help to Jojo and Jojo tells him that he can help by telling all the animals. The lion doesn't want to tell the animals, but Jojo insists that he do so. So Lion has a meeting and tells all the animals that Jojo is HIV positive. Cat, a puppet character, asks Jojo if he will also get HIV. Jojo tells Cat that he will get HIV but he doesn't know how that will happen. Jojo also doesn't know what happens to animals if they get HIV. The doctor arrives to answer the animal's questions. Jojo asks the doctor how he got AIDS.

Puppet play: feelings about HIV in the family

The researcher sets the play scene. She introduces the characters, it is about a family, there is a grandmother, mother, father, brother and sister. The mother is HIV positive. Each person in the family feels different things about that. The researcher names a feeling and Ondela attributes the feeling to a family member and explains why they feel that way. The grandmother is sad because she is HIV positive; Daddy is worried because he is dying, he is also HIV positive; the brother is cross because his mother is sick. He does not tell his mother how he feels. The sister is sad because her mother is sick. The mother doesn't feel anything. The family does not tell each other how they are feeling. The children argue about who is going to fetch treatment for the mother. The sister prefers to play so the brother has to do it. The brother is cross with the sister. The brother worries a lot about his grandmother, father and mother because he thinks that they are going to die. The brother does not tell his friends at school, because if he does they will be frightened of his mother. They will be frightened because they don't know what HIV is.

What happens to the family?

The children will get HIV from their mother. The grandmother will die and the mother will bury her. The father will be sick and then he will die. The sister and brother will finish school, get jobs and they will get treatment for HIV. The mother will die.

Feelings

Ondela colours in the cheetah spots to show how he feels. Ondela starts by using orange for happy. The researcher reminded him to show how he is really feeling and not to colour what

he thinks the researcher would like to see. He then completes the rest of the spots in black for worried.

Ondela is worried that ...

Ondela said that he is worried about getting HIV from his mother. He showed high levels of anxiety talking about this as he was wringing his hands and looked downwards with little eye-contact. He knew that this could happen if he used her toothbrush but he didn't use her toothbrush. Ondela knew that no-one was going to get HIV from his mother but he still worried that he would get it. He repeated that HIV affects other people and that HIV is painful.

3.4.4 INTERVIEW FOUR

Puppet play: the animals talk about HIV

The researcher set up a play scene, using the crocodile character and animals from the puppet play in interview three. She told Ondela that she would start the story and he could finish it. Ondela agreed. The play scene: after lion had told the animals that crocodile was HIV positive all the animals had different ideas about HIV. They got together and spoke about their ideas. Spider told the animals to keep quiet because he wanted to say something. All the animals kept quiet and listened to spider. The researcher invited Ondela to speak for spider. Ondela did not wish to play this role. The researcher continued with the story. Spider said that he had been listening to the animals talking and he thought that most of the animals were confused and scared.

The researcher asked Ondela what he had heard people saying about HIV. Ondela said that he heard some guys talking about HIV and they had said that HIV is deadly and that people with HIV die. These guys also said that "those who are HIV positive don't talk". People who are HIV positive hide their status and they don't tell anybody. Ondela wasn't sure why HIV positive people don't tell, maybe because they are scared. Ondela said that he doesn't believe those guys. However, in response to a direct question, Ondela admitted that HIV causes people to die. Again in response to a direct question, Ondela said that he worries his mother will die. *Ondela became tearful.* Ondela repeated that he couldn't do anything to change that- "I can't do anything, I can't do anything".



The researcher introduced the crocodile's son that Ondela named Dekita. Dekita was hiding in the bushes and heard the animals talking. He then ran to his mother because he wanted to be near her. Ondela refused to play Dekita's role and did not want to say anything to Jojo. In response to researcher questions Ondela said that he does not ask his mother about HIV even though he would like to. Ondela explained that in the past he had tried to ask his mother questions but she had become cross with him and told him to "get out of her way". Ondela said that he wanted to know about HIV and he wanted to be taught about it.

Ondela said that he felt scared because he is afraid that he will get HIV from his mother. He worries about this a lot but he has not told anyone about his fear and he thought that he would harm other children and that he would die. At this stage Ondela was tearful and withdrawn. The researcher spoke about feeling scared, acknowledged Ondela's feelings. She encouraged Ondela to speak more about his fear but he did not want to.

The HIV positive man

Ondela drew a picture of an HIV positive man. He described the man; the man was worried because he has AIDS and he will die. His family asked him how he got AIDS, but the man did not know. His family treated him well; they give him treatment and parties. The man does not tell people at school about his status because they will be naughty toward him. They will tell him that he has AIDS and that will make him feel sad. However, Ondela acknowledged that "it is not right to keep a secret, people mustn't". Ondela doesn't want to tell anybody about his mother's status,

" I don't want to tell anybody. They will tell others. They will think that I also have it".

Ondela said that he knew of other children that had mothers who have HIV and he believed that they thought the same things he did,

"I think that they think their mothers will also die".

Furthermore, Ondela thought that other children would not want to be friends with children whose mothers are HIV positive. Ondela acknowledged that there were other things that he thought that he did not wish to tell the researcher or anyone else.

What can be done to help Ondela?

Ondela did not think that there was anything anyone could do to help him.

Researcher: What kinds of things can people do to help children whose mommies are HIV positive?

Ondela: I don't know

Researcher: Do you think there might be something that people can do to help?

Ondela: Nothing.

CHAPTER FOUR-THEMATIC INTERPRETATION

4. Emerging patterns of meaning as themes

A heuristic reading of the narratives allowed aspects of the participant's accounts to emerge in terms of issues or problems and factors that gave rise to and maintained them (Bromley, 1986). These patterns of meaning or themes have been presented under broad headings that organise the participants' accounts in terms of their understandings and with reference to the relevant conceptual frameworks that guided their identification.

4.1 Thematic interpretation: Thandi

4.1.1 THANDI'S RELATIONSHIP WITH HER MOTHER

During the interviews Thandi reported on varying interactions with her mother through stories around drawings or in puppet plays between mother and daughter characters. Thandi's discourses about her mother can be grouped according to interrelated expectations and assumptions held by Thandi. The mother as the figure of authority; the mother as the provider and protector; the mother as HIV positive and healthy, and the mother that is sometimes ill. Each discourse represents varying orientations in Thandi's response to her mother. As Thandi manages her mother's HIV status discourses overlap or become salient in accordance with Thandi's needs and concerns.

Mother as provider and protector

The absence of the father extended Funeka's parental duties, especially in financial terms. Funeka is dependent on welfare and she manages to earn a small income. Funeka expressed concern over her children's financial future and her ability to meet their material and physical needs.

Thandi's perception of her mother as protector and provider was evident in her dependency on her mother to protect her from nightmares and people that scared her and to provide her with a home, food and clothing. When Thandi spoke about her mother she referred to her mother's work. In this capacity her mother is economically active and a provider of food and material needs. Thandi drew her mother carrying food and she spoke about her mother's role in buying her food and clothing.

Mother as authority

Funeka's expectations of Thandi were mostly around obedience to household rules. These included explicit rules with regard to helping with chores, carrying out instructions, being home at a certain time and implicit rules around Funeka's needs for privacy and time to rest. Thandi's needs such as playing with friends were supported but only after her responsibilities at home had been completed.

Another aspect of Thandi's relationship to her mother was one in which she perceived her mother as an authority figure. The theme of obedience to the rules in the family and to authority figures is introduced in the family puppet plays and extended in Thandi's narratives about her mother. Funeka is portrayed as the rule-maker that needs to be obeyed. Thandi spoke about her obedience to rules and the non-negotiable nature of these. Often reparative behaviour, such as making tea was apparent when Thandi disobeyed her mother. Thandi extended her obedience to authority to school where she experienced a sense of satisfaction around being 'good'. In this manner Thandi would portray herself as the 'good' child and affirmation of obedient behaviour was forthcoming from her mother and according to Thandi from her school teachers.

Thandi's perceptions of her mother as a protector, provider and authority figure reflect expectations and assumptions she has of her mother. The reciprocal nature of these can be seen in Funeka's approach to child-rearing and her adoption of specific roles within the family.

Healthy mother versus ill mother

After five years of relative health, Funeka was experiencing a number of physical symptoms of illness. Despite emphatic statements that she was strong and healthy, Funeka expressed her concerns about her fluctuating CD4 counts and both at home and with the researcher she spoke about being 'stressed', 'tired' and 'needing her rest'. It was difficult to penetrate Funeka's public face of health and most often her reference to physical symptoms occurred outside the interview. In her account Funeka reflected a tension between maintaining health and deteriorating health.

Thandi's understanding of her mother's HIV status similarly reflected a tension between maintaining a representation of a healthy mother versus an ill mother. On the one hand

Thandi referred to her mother as 'HIV not AIDS' thereby promoting her healthy status. Thandi's view of her mother as healthy stems in part from Funeka's message about the difference between HIV and AIDS. In terms of Thandi's knowledge, Funeka was satisfied that she knew to distinguish between these aspects of the disease. In the interviews, Thandi associated being HIV positive with membership of a support group that her mother attended. People attending the support group are happy and healthy.

On the other hand, Thandi showed concern with her mother's ill-health and impending death. In one vignette, she spoke about her mother being tired because she cleaned, walked and worked too much. This discourse reflects Funeka's explanations when she responds to Thandi's enquires about her health, in that Funeka speaks about her ill-health in terms of tiredness and stress. Thandi further portrayed her mother in terms of illness in that her mother took drugs and saw a doctor. She later played out in a mother-daughter puppet play themes of illness and tiredness with regard to her mother.

As reported by Funeka, Thandi showed vigilance around her mother's health. She was sensitive to her mother's needs with regards to needing 'time to rest' and help with household chores. Thandi was particularly concerned with her mother's upcoming hospitalisation. She expressed this in terms of physical symptoms of illness and death.

Thandi's response to her mother's ill-health is situated within broader knowledge bases and understandings held by Thandi.

4.1.2 THANDI'S KNOWLEDGE ABOUT AND UNDERSTANDING OF HIV/AIDS

Transmission of HIV

During the last interview Thandi educated the researcher about how HIV is transmitted and she attributed her knowledge to her mother and to "things I think in my brain". Thandi believed that HIV is transmitted through contact with blood, saliva, contact with dried blood and that crying caused AIDS. She further associated HIV and AIDS with specific feelings, relationships and consequences. Because Thandi's knowledge is couched within certain beliefs it will be discussed in terms of Thandi's reasoning.

Thandi explained how touching a bleeding person when you have an open sore gives you AIDS,

"if some-one has an open sore on their hand and if you touch that sore, something goes into your skin and from there into your blood. The blood doesn't like that thing from the sore and then you will have AIDS".

She further believed that if there was dried blood on a jersey belonged to an HIV positive wife then others who wore that jersey would be at risk for getting HIV. Saliva transmits HIV if a wife spits into her food then the husband who eats the same food could get HIV from his wife's saliva. Thandi explained that crying excessively causes AIDS. Her explanation centred on the idea that crying causes water loss from the legs resulting in thin legs, a symptom signifying the presence of AIDS.

Associated factors

HIV was considered an illness with respect to the central role accorded to doctors and nurses in diagnosing and treating HIV/AIDS. Thandi associated AIDS with physical symptoms such as weakness, thinness and mouth sores. In one story, the central character has mouth sores, he is weak and eventually he goes to hospital where he dies. In discourses about her mother and in puppet plays, Thandi associates hospitalisation with illness and certain death

Thandi repeatedly spoke about HIV in terms of people that are infected with it and the impact this had on their relationships with others. Her ideas were expanded throughout the interviews as she discussed her beliefs about how people cope with being HIV infected. These take the form of issues and problems associated with HIV infection. In particular, HIV infection occurs in a couple where both are afflicted. Other people react to HIV infected persons with fear and anger. The consequences of these beliefs were evident in stories where the characters reiterate the need for secrecy. Similarly Thandi requires secrecy around her mother's status. Since Thandi spoke about HIV positive people rather than HIV, her ideas and understanding manifested in what she believed HIV positive people thought and felt. She attributed feelings of sadness, anger and happiness to HIV infected people, who consistently did not want to be HIV positive.

4.1.3 ANTICIPATING FUNEKA'S DEATH

Sadness and worry

An HIV positive mother character and her daughter character were used in a puppet play in which Thandi played out aspects of her relationship with her mother and attributed feelings to the daughter puppet regarding having a mother that is HIV infected. In the puppet play,

Thandi as the daughter, made her mother tea and wished to sleep with her. The daughter was very sad,

"Little girls whose mommies are HIV positive, are sad."

During the play, Thandi acknowledged that she has a "biiig problem", because her mother has HIV. Thandi identified with the little girl's feelings of sadness and directly expressed sadness about her mother dying in the feeling games. In the same play, Thandi's character is worried that the HIV positive mother is going to die. Thandi's character spoke openly to her mother about her fear that she would die. The mother reassured her that she would not die, reflecting a real-life experience. In direct reference to her worry around her mother dying, Thandi explained that she was concerned that her mother would die from causes other than AIDS.

Thandi played out her anxiety over her mother's death in the last extensive puppet play. Thandi produced a complex story in which the central theme is death. The story neatly incorporated most of the themes and ideas introduced by Thandi through the interviews. Thandi played out her association of hospitals with death where despite initial reassurances by the doctor that the patients were fine, these characters died. She then held a funeral for both of the dead characters, playing out mourning processes, expressed through crying and screaming and shared her understanding of death as final,

"she is gone now, she is not here anymore in the world, those two. Not here in the world".

Thandi explained that the dead characters are "up, with Jesus".

In the same story the mother got AIDS and died. This was the third character to die in the story. In her description of the above puppet play, Thandi spoke about life threatening experiences she had witnessed. She spoke about dangers in her environment that she found threatening and was concerned that these would threaten her mother's life as well.

Wishes

In a puppet play, Thandi prayed that God would help her mother,

"oh, God, the mother she must not be dead and give her the power to be right"

As her prayer above suggests, at times Thandi wished that there was a cure for her mother. When she spoke about the future, Thandi wished that her mother would remain HIV positive and not get AIDS.

Talking about death with her mother

Thandi was able to directly discuss her concerns about her mother's death from AIDS. Thandi repeated her mother's reassuring statements that denied the onset of death. She reported that her mother had told her that she was not ready to die yet and would only do so once certain projects such as house renovation had been completed. Thandi further informed the researcher of instructions that her mother had left regarding some of her possessions after she dies. However, Thandi's underlying fear was evident when she immediately reported on her mother's symptoms (failing eyesight and growth under her eye) and on an upcoming overnight hospital admission. Thandi was worried that her mother might die in hospital,

"I think she must not be dead".

4.1.4 NOT TELLING

Secrecy outside the home

Thandi had not told any of her friends that her mother is HIV positive. Thandi believed that by telling a friend everybody would end up knowing,

"if you tell they are going to tell another one and then its gonna get bigger and bigger and bigger".

Furthermore, people would tease her about this,

"...if they say can you give me your crayons and I said no...they gonna say, na, na, na your mother is HIV, na, na, na, na. That's why I don't want to tell them, I feel cross".

Thandi played out her need for secrecy in that her story characters did not wish to tell. When one character did confide in a friend he was made to promise to keep the secret. Thandi's character informed him that he was the only person she told.

The consequences of telling for Thandi were made apparent when one of her characters was going to commit suicide by stabbing himself if people knew his status. Thandi believed that suicide was an option for many HIV positive persons if others knew. Thandi stated that,

"AIDS is trouble. Other people are scared of AIDS."

She explained, again using the example of a couple, that if a couple is infected with HIV they have to run away because other people are scared of AIDS.

According to Thandi people are "naughty" toward HIV positive people as they tease them. However, underlying her fear of telling seems to be Thandi's belief that,

"maybe they gonna, don't love her because she is HIV."

HIV meant the loss of love and rejection for Thandi.

Although Thandi had chosen to keep her mother's HIV status a secret, she conceded that it was okay to tell close family such as parents, a spouse and one friend only. Thandi admitted that she would like to tell one friend after a puppet play where a girl confided her mother's HIV status to her best friend. Thandi denied experiencing discrimination over her mother's HIV status in that no-one had been naughty to her.

Avoidance at home

Thandi extended her not telling behaviour to include an unwillingness to talk about HIV at home. She would only speak to her mother about HIV and only at her mother's initiation, Thandi did not ask her mother questions. Thandi was adamant that,

"I don't want to know everything about HIV/AIDS"

and for this reason she felt sad and cross when her mother speaks to her about it. Funeka's account of Thandi's reluctance to speak about HIV confirms Thandi's general avoidance of the topic.

During the interviews, Thandi avoided talking about HIV/AIDS by informing the researcher that she did not know what HIV was, that she could not remember what her mother had told her about it and that she did not want to talk about it. Thandi consistently expressed feelings of anger, sadness and worry when she was requested to talk about HIV/AIDS.

4.1.5 THE WORLD IS UNSAFE

Life-threatening dangers in Thandi's world

Thandi extended her concern over her mother's welfare by worrying about her safety when she came home late at night. Her concern about this was not directly related to her HIV status but may be rooted in Thandi's wider fears about the dangers or threats to life that are present in her residential area. She voiced her fears that a taxi driver who she named a "killer" would kidnap her mother and kill her or that she would be raped by "coloureds". Thandi worried that her mother would die,

"she is gonna be dead"

Thandi attempted to minimise threats or dangers by telling her mother not to come home late. However, her mother does not listen to her and Thandi reported being angry with her mother because she believed that her mother didn't care.

Thandi's preoccupation with an unsafe world revealed itself in her nightmares- she was afraid that robbers would come into her house and stab her. Her puppet plays showed similar concerns. During the last puppet play Thandi played out the death of two characters, one is fatally stabbed and beaten by robbers and the other is fatally wounded in a car accident. These incidents were based on real-life experiences in that Thandi had witnessed a school child being knocked over and killed by a car and a man being stabbed near her house. Thandi spoke about keeping herself safe in that she knew not to run in the street in case a car knocks her down. She did not go out when it is dark and she expressed her anger at both her mother and elder sister when they did.

School is unsafe

Thandi portrayed her school as an unsafe place, where "naughty" boys beat other children, draw 'tattoos' on their arms, smoke cigarettes and destroy the classrooms. Thandi also believed that the toilets at school are haunted and that the ghosts had killed a school child. At school, Thandi keeps herself safe by running away from the bad boys, not getting involved in fights with other children and by not being naughty.

4.2 Thematic interpretation: Ondela

4.2.1 ONDELA AND ZINZI

The relationship ties that Ondela has with his maternal grandmother offer a different perspective in terms of the caregiving and parental role adopted by Zinzi. Ondela refers to his mother as "makazi" or aunt and he calls his grandmother, "mama", but both women parent Ondela. From Zinzi's accounts it seems as though Ondela enjoys a closer relationship with his grandmother but the nature of the 'closer relationship' is unclear. Although Zinzi was able to give information about Ondela's behaviour pre and post disclosure and about Ondela's concern over her health, she does not talk to him about his feelings or behaviour.

Ondela's accounts about his mother suggest feelings of anger and concern over her consumption of alcohol. As he says, "my mother is nice when she is not drunk". He made three references to this behaviour. Ondela further described the lack of communication with

his mother in general and about HIV/AIDS. His attempt to speak to his mother was met with rejection in that his mother told him to,

"get out of her way".

4.2.2 ONDELA'S KNOWLEDGE ABOUT AND UNDERSTANDING OF HIV/AIDS

Ondela's factual knowledge about HIV/AIDS came from various sources. He had received HIV/AIDS education at school and he had heard "some guys talking about HIV". It seemed as though he was less secure about the veracity of the information that he had heard from peers. For the most part his understanding of HIV/AIDS showed obvious gaps of which he was aware. Ondela repeatedly voiced his concern, both in play and during exploration of his thoughts, that he did not know how HIV was transmitted. Toward the end of the interviews (interview three) he was able to ask for information and said that he wanted to know about HIV and he wanted to be taught about it. In interview one and two Ondela denied knowing anything about HIV and did not wish to discuss it. However, as the interviews progressed Ondela was slowly able to share what he knew about HIV.

From school Ondela knew that HIV could be spread from one person to another. He knew this happened if you touch an HIV infected person that is bleeding and you have an open sore on your hand. However, he did not know how else it can be transmitted. His teachers had also told his class that they must not go to strangers because they would infect them. Ondela knew that to have HIV is painful because his mother had told him so. Ondela learnt from overhearing conversations that HIV is deadly and that people with HIV will die. He also heard that people who are HIV positive don't talk about it and hide their status. Ondela was not sure why they did this but supposed it was because they were scared.

4.2.3 MY MOTHER WILL DIE

Linking HIV and death

Ondela first mentioned a link between HIV/AIDS and death in the third interview during a puppet play. In the stimulus situation introduced, only the mother was HIV positive. However, during Ondela's play the whole family became HIV positive and the elder members; grandmother, father and mother all died while the children received treatment and lived.

Death and his mother

In the following interview Ondela shared knowledge that HIV is "deadly" and he voiced his concerns about his mother. Ondela acknowledged that he worried that his mother would die. He became tearful and repeated that there was nothing he could do about that. Later in the interview in response to a puppet play about an HIV positive crocodile and her son, Ondela shared that he is afraid that he will die too. Ondela repeated his concern about HIV and death when he attributed feelings and thoughts to an HIV positive man that he had drawn. This man is worried "because he has AIDS and he will die". The centrality of this concern became apparent when Ondela thought that other children whose mothers were HIV positive would also think that their mothers would die.

"I think that they think their mother's will also die"

It is important to note that Ondela did not receive information about the link between HIV and death from his mother. He heard this information from other people and thus has not had the opportunity to verify it nor to share his fears about this possibility with anyone. He has been carrying this information in silence.

4.2.4 CONTAGION FEARS: I WILL GET HIV AND DIE TOO

In the third interview during the family puppet play Ondela introduced another fear. In the puppet play the children get infected with HIV from their mother. While exploring his worried feelings at the end of the play, Ondela said that he was worried about getting HIV from his mother. He thought that this could happen if he used her toothbrush but he never did. Ondela struggled with making sense of his fears, in that he knew he couldn't get HIV from his mother but nonetheless he worried that he would get it. In the fourth interview Ondela repeated his fear of getting HIV from his mother. He thought that if this happened he would harm other children by passing the HI virus onto them, and he would die. Ondela was unable to talk about this further; he became tearful and withdrawn.

4.2.5 NOT TELLING

In the fourth interview Ondela was better able to explore his reasons for not telling others about his mother's HIV status. During the family puppet play, Ondela attributed some thoughts to the brother in the family. The brother doesn't tell anyone about the mother's HIV status because they will be frightened of his mother and they are frightened because they "don't know what HIV is". Similarly he attributed thoughts onto the HIV positive man he drew who did not tell his friends at school either. The reason for this was because the HIV

positive man believed that his friends would be naughty toward him by telling him that he had AIDS and that would make him feel sad. Later in the interview Ondela was able to own his thoughts and feelings about not telling. He believed that if he disclosed his friends would think that he had HIV too and that other children don't want to be friends with children whose mother's are HIV positive. Furthermore, if he told friends they would tell others and then everybody would know.

Ondela reported that it was not difficult for him to keep his mother's status a secret. However, he commented on his own behaviour and said that,

"it is not right to keep secrets, people mustn't"

This view is consistent with his puppet play in the third interview where Ondela as an HIV positive crocodile character wants to tell all the animals about his status.

4.2.6 WORRY AND HELPLESSNESS

Worry

Ondela consistently chose worried as his predominant feeling and as the interviews progressed he was able to at least name what it was that made him worried. During the second interview, Ondela filled a "feeling bottle" entirely in black, the colour that symbolised worried feelings. He was not willing or able to say what it was that made him worried at this stage. He consistently refused to respond to questions that attempted to elicit discussion around his worried feelings, by saying "nothing". Slowly Ondela attributed feelings to characters in the puppet play and to figures that he had drawn. In the third and fourth interviews, Ondela was able to own these feelings and reported that he was worried about the following:

- That his mother would die
- Contracting HIV from his mother
- That he would harm other children
- That he would die

In the second interview Ondela said that it was sad for him that his mother was HIV positive and that,

"I was painful at the time she began HIV (disclosure)".

However, he was not able to talk about his feelings. Ondela's eventual disclosure of his fears were preceded by and accompanied by high levels of anxiety.

Helplessness

Although not directly articulated as such by Ondela, a sense of helplessness came through in his responses. When he spoke about his mother dying, Ondela added that there was nothing he could do to change that reality for himself,

"I can't do anything, I can't do anything"

In response to questions about what Ondela thought might help him or what people could do to help him, he responded simply by saying, "nothing".

CHAPTER FIVE-DISCUSSION

5.1 Introduction

This study offers an exploration of the complexity inherent in the experiences of two children living with mothers who have HIV. It is also an attempt to allow the 'voices' of AIDS-affected children to emerge as they tell their stories in terms of their situated lives. The employment of a case study approach using qualitative methodology is in contrast to quantitative studies that dominate research into the effects of parental HIV infection (Wild, 2001) and that 'measure' childhood adjustment according to specific and decontextualised domains (Forehand et al., 1997). Instead, children were able to communicate their views and feelings about what maternal HIV-infection meant to them in terms of their every day lives. The use of play techniques facilitated the children's engagement in the play interviews as they spoke about issues that caused them distress. The experiences of AIDS-affected children emerged as part of a wider context in which maternal HIV infection as a stressor was understood as a complex entity that was embedded in and mediated by the children's developmental stage, historical familial relationships, maternal responses to HIV-infection and broader social factors such as AIDS-associated stigma.

Processes in the children's lives that engendered vulnerability are discussed with regard to recommendations for intervention. This study will then be evaluated in terms of strengths and shortcomings, and suggestions will be made for further research.

5.2 Developmental factors

The developmental maturation of the children contributed to their cognitive capacity to understand HIV/AIDS as a virus or syndrome and thereby to make sense of maternal HIV in these terms (Walsh & Bibace, 1990; van Dyk, 2001). Children in the senior primary school phase, aged 10-12, show mostly concrete thinking but are able through logical reasoning capacity to understand the concepts of cause-and-effect and the transmission of disease and HIV. For example, both children in this study had a clear understanding of how they could get HIV from a bleeding person if they had an open wound on their hands. However, their understanding was bounded by their own everyday frames of reference. This study concentrated on family contexts as the key environment of influence, but the children learnt about HIV/AIDS from school, their peers and through interactions with their community. Children's exposure to peer group and community beliefs about HIV/AIDS increase as they

grow toward adolescence. The formation of relationships beyond the family and the need for acceptance by the peer group introduces new and different points of view that may differ from family ideals and practices. Furthermore, at this age, children are susceptible to the acquisition of false beliefs, in that they form an overarching conceptualisation of causes that combines real causes with misconceptions (van Dyk, 2001). In this study, the children's exposure to alternate beliefs introduced competing perceptions of HIV-infection, that is between the actions of their mothers and prevailing community views of HIV/AIDS. Discussion of the individual cases will illustrate the situated context of how the children's perceptions emerged and the consequences of their beliefs.

5.3 Thandi and Ondela: particularity versus generalisability

The two children experienced their mother's HIV infection in unique ways as informed by personal, developmental and contextual factors. The significance of maternal HIV infection for each of the children showed similarities but also differences, and will be discussed separately for each child in order to illustrate these differences as part of a situated experience. Similarities will be highlighted as part of a broader approach to intervention. Stake (2000, p.439) asserts that in case study method, "the search for particularity competes with the search for generalisability." The value of the particular is often overshadowed by the search for general laws. However, he argues that a single case study can be seen as part of a process tending toward generalisation, and the complexity with which a single case is studied is a strategic decision made by the researcher. In this study, the value of the children's situated experiences lies in the manner in which meaning is constructed around maternal HIV and the complexity inherent in these processes. However, the processes that engendered vulnerability to stress are highlighted in terms of other similar cases, reflecting generalisation of the particular.

5.4 Discussion of Thandi

5.4.1 Contextual stressors

Funeka's HIV-infection was not viewed as a "simple index of risk" (Luthar & Zigler, 1991, p.10). Along with having to cope with the emotional sequelae and physical symptoms of HIV-infection, Funeka experienced economic stressors as she struggled to feed her family, marital conflict and family stressors as she headed up a household on her own. Social pressures such as stigma were denied but she complained about feeling stressed by her job. Along with being HIV positive, economic difficulties, single-parent headed households and

marital difficulties are understood to be significant stressors (Luthar & Zigler, 1991) that may disrupt and undermine parenting ability (Armistead et al., 1995).

Thandi identified structural features of her environment (Dawes & Donald, 2000), that she thought were potentially threatening to her and her family. Although Thandi's preoccupation with her safety and that of her family may stem from her anxieties around her mother's HIV-infection and anticipated death (Worden, 1996), her concern with violent crime in her residential area was borne out by the incidence of such crimes. Figures issued by the Grahamstown Police Services (2002) indicate that in 2002, 72 rapes including attempted rape, were committed in peri-urban areas surrounding Grahamstown. This figure stands in stark contrast to the 10 rapes that were committed in residential areas closer to the centre of town. 346 cases of assault including domestic violence and assault with intent to grievous bodily harm were reported in one week (1st-7th April 2003) in the same area (Grahamstown Police Services, 2003). Dawes & Donald (2000) state that during the primary school years the impact of community characteristics such as violence on the street impact children through the stress it creates for the parents. However, Thandi has witnessed the consequences of stabbings and car accidents and was well aware of community discourses about the danger of gangs that kill and rape. Both Thandi and Funeka experienced a number of significant stressors over and above HIV-infection.

5.4.2 Avoidance in the family: secrecy, stigma and shame (see 1.2.7.c)

An exploration of Funeka's response to HIV-infection is not the focus of this study, but features of this will be highlighted as Funeka denied aspects of her HIV-infection in the family. Funeka's apparent openness about her HIV status and around HIV/AIDS-related issues as suggested by her work, was not apparent in the home. Although complete denial was not evident, Funeka had decided not to tell her husband about her HIV status and the manner in which she disclosed to Thandi and communicated to her about HIV/AIDS shows differential denial, where some aspects of HIV-infection were discussed and others avoided. Differential denial was evident in the manner in which Funeka spoke to Thandi about death. This was in part influenced by her orientation to HIV/AIDS that emphasised a stance illustrated by the adage- 'living positively with AIDS' that endorses a certain life-style for HIV positive persons. This slogan focuses on life rather than death (Soul City, 2001). In her interactions with Thandi the focus on life and health was pronounced to the degree that it denied death. Funeka avoided talking about the sexual transmission of HIV in general and

with reference to herself. Funeka had decided not to tell Thandi about the sexual transmission of HIV, as she believed that Thandi is too young for sex education. However, Thandi was given a booklet to read (Soul City, 1996) that contained explicit information on the sexual transmission of HIV and on condom usage.

The contradictions apparent in the selective provision of information and other avoidant behaviour may be understood in terms of Funeka's feelings about her HIV-infection and the consequences of this for Thandi. As Nagler et al., (1995) point out, secrets about HIV may be an attempt by the mother to safeguard her relationship with her children thereby avoiding rejection by them. As Brown-Smith (1998) argues silence around certain topics protects certain family members from having to deal with potentially threatening feelings and consequences. Funeka's role as a mother may be undermined by feelings of shame that she has about bringing harm to Thandi directly through infection and indirectly through her own death. Shame influences Funeka's ability to speak to Thandi about her HIV-infection, possibly as this puts her at risk for losing her worth and place of importance in Thandi's life. Funeka's avoidance may be an effort on her part to protect Thandi from distress and also to protect herself from dealing with her daughter's responses (Papp, 1993).

On a broader level, secrecy is understood to maintain avoidance of subjects in the family thereby influencing what can be said about HIV/AIDS to whom. The keeping of secrets became an issue during the interviews in that Funeka initially misled the researcher about the whereabouts of her husband and the nature of her interaction with Thandi on HIV/AIDS-related issues. It seems as though secret-keeping provided a familial defensive function so that certain topics could be avoided. Literature on the impact of AIDS-associated stigma indicates that in response to pejorative community views about HIV, AIDS-affected families may keep HIV infection a secret to varying degrees. It is proposed that Funeka's avoidance of certain HIV/AIDS-related issues in the home perpetuated and indirectly confirmed broader views of HIV as something that cannot be spoken about. Funeka's silence indirectly communicated her shame to Thandi in a community context that stigmatises HIV-infection. Furthermore, it may be that Thandi has taken on her mother's shame as part of her identity (Nagler et al. 1995). In this manner, Thandi feels shame in her association with a mother who is HIV-infected. Thandi's decision to keep her mother's status a secret shows her avoidance of evaluating others and her beliefs that HIV/AIDS is 'bad'. The act of hiding from others due to moral transgression or 'badness' is often associated with feelings of shame

(Barrett, 1995). Thandi beliefs about the badness of HIV/AIDS are illustrated through her attributions of what others believed. In this respect, she thought that other persons are afraid of HIV, that they would not love HIV-infected persons and that HIV-infected persons should run away or commit suicide. In response to perceived community perceptions Thandi expected to be rejected and feared judgement.

5.4.3 Communication and emotional support in the home

Parental involvement, including the provision of adequate information has been identified as a protective factor in the literature on stressors in childhood (Garmezy, 1998) and childhood bereavement (Worden, 1996). Family secret-keeping, Funeka's and Thandi's shame around HIV infection had an impact on Funeka's ability to communicate openly with Thandi and on Thandi's receptiveness to HIV/AIDS-related information. Funeka has the skills and information to communicate with Thandi but she does not do so, possibly to avoid her daughter's judgement. In turn, Thandi does not wish to talk about HIV/AIDS either which leaves her isolated both within and beyond the family. A cycle of avoidance is set up between Thandi and her mother, wherein only certain HIV/AIDS related topics can be spoken about and then only in certain ways. For children between the ages of 5 and 10, rules and the adherence to these are seen in absolute terms (van Dyk, 2001) and this is apparent in Thandi's respect for her mother's rules as shown by her expectations of 'mother as authority'. Talking about HIV/AIDS in Thandi's family occurs according to underlying implicit rules that disallow the discussion and expression of different thoughts and feelings.

Communication about HIV/AIDS refers to the sharing of factual knowledge as well as to the sharing of related feelings and thoughts. The latter is largely absent with respect to mother-child interactions. Funeka does not know what Thandi thinks and feels about her HIV-infection, nor does she know what factual knowledge she holds beyond that which she wishes Thandi to know. Thandi is aware of her mother's distress indirectly through Funeka's complaints of tiredness and stress and she responds to this by taking on a caring and protective role herself. The distance between mother and daughter is particularly pronounced with respect to emotional support offered by Funeka. Worden (1996) discusses the idea of "discrepancy of perception" that refers to the accuracy with which a parent (caregiver) sees how a child is feeling or behaving when compared to the child's report. An accurate perception is required to make the child feel secure and validated. Children look to their parents to validate, mediate and explain their feelings. When there is a wide discrepancy

children find it difficult to trust their feelings. Funeka's role as parent seems to be active around provision of material needs and discipline in her role as protector, provider and authority. She is not able to encourage the expression of affect and thereby play an emotionally supportive role in her relationship with Thandi. She responds to her own and Thandi's fears about the future in a practical manner by organising foster care and welfare grants, that are in themselves important preparations. However, Funeka negates the underlying emotional aspect of her own and her daughter's experience.

5.4.4 Anticipation of her mother's death (see 1.2.7.b)

Worden (1996) discusses two important processes that mediate children's grief, namely comprehension of the cause of death and the relationship with parents who play an important role in facilitating grief by allowing children to experience and express the emotional aspects of loss. In Thandi's home, the dominant mother-child discourse around the long-term consequences of HIV infection focused on life and health. A distinction was made between HIV as associated with health and AIDS as associated with death. In the short-term this orientation made HIV-infection less threatening and manageable on a daily basis. Thandi's perception of her mother as both HIV positive and healthy allowed her to manage her mother's infection as distinct from dying. When Funeka is healthy she can continue to fulfil her parental roles of provider, protector and authority figure. However, in the long-term it became difficult for Thandi to separate health or HIV from anticipated death or AIDS, especially when Funeka showed signs of physical illness. Thandi's appraisal of her mother's illness in terms of approaching death evoked feelings of sadness, anxiety and hope around loss that is associated with an anticipatory grieving process (Pivnick & Villegas, 2000; Sweeting & Gilhooly, 1990). These feelings were not expressed to or validated by Funeka who tended to reassure Thandi that she was not going to die yet, further increasing uncertainty around dying.

Thandi associated AIDS with physical symptoms, hospitalisation and death. The consequences of her understanding in these terms was evident in the fear she expressed about the possibility of her mother dying when she had to go to hospital. The objective characteristics of her mother's health were overshadowed by Thandi's appraisal of the situation. In reality, Funeka's overnight hospitalisation was an attempt to get early morning transport to an eye-clinic so that she could obtain a stronger prescription for spectacles. However, for Thandi, hospitalisation signified possible death.

5.4.5 Misconceptions and meanings that engender vulnerability

Children's perceptions of their contexts are central to an understanding of how they engage with and develop in their world (Dawes & Donald, 2000). Thandi made sense of HIV/AIDS in general and of her mother's HIV infection based on information that she did and did not have, in interaction with the way in which maternal infection was dealt with in the home and within a broader community context. The provision of information in the form of reading material, did not increase Thandi's knowledge of HIV/AIDS. The absence of information without maternal guidance allowed Thandi to develop misconceptions about HIV transmission, in that she believed that HIV could be transmitted through contact with saliva and dried blood. In the absence of clear and comprehensible information and opportunity to ask questions, children may fill in the gaps with fantasies, ideas and thoughts of their own, that are often frightening (Lewis, 1995).

Thandi's capacity to understand issues such as the transmission of HIV, parental illness and death is partly determined by her capacity for abstract reasoning and developmental maturation (Lewis, 1995; Walsh & Bibace, 1991) (see 1.2.6). Information or reading material that was given at disclosure, took the form of a once-off event and no further explanation of or guidance on reading material was given. Disclosure of HIV status to children should occur continuously in response to children's growing awareness and their need to ask questions. Children of different ages require different levels of HIV/AIDS-related information as they develop into adolescence and beyond. Information given should be congruent with their intellectual capacity to understand concepts such as disease and death (DeMatteo et al., 2002). The context of knowledge acquisition influenced Thandi's conceptions of HIV/AIDS to a large degree (Armistead, et al., 1999; Young et al., 2001). This context was characterised by maternal avoidance and feelings of shame that encouraged secrecy. Information that was given served Funeka's needs to avoid issues around the sexual transmission of HIV and to reassure Thandi that her HIV infection posed no immediate threat.

In the absence of clear information and emotional support, Thandi associated maternal HIV infection with fear and perceived that others would be judgmental about HIV-infected people and those with AIDS. She experienced shame associated with her mother's HIV status and expected rejection. Thandi isolated herself, she avoided talking about HIV and kept her mother's status a secret. She held misconceptions about the transmission of HIV that

potentially increased her vulnerability to infection and her fear of HIV/AIDS. She was vigilant around her mother's deteriorating physical health and she expressed sadness and anxiety as she anticipated her mother's death in a family context that avoided active engagement at an emotional level. Maternal HIV infection introduced insecurity into Thandi's world. Not only does it threaten her relationship with her mother in the long term, through her mother's anticipated death, but also instils a sense of mistrust in and fear of building relationships outside the home. It is not safe for Thandi to tell peers or other adults about her mother's HIV status as they could potentially reject her on these terms.

5.5 Discussion of Ondela

5.5.1 Family relationships

Ondela's experience of his mother's HIV infection will be discussed in broad terms that illustrate the key processes that exacerbated his fear of HIV and his concern with his mother's anticipated death. His experiences are situated within a family context where his mother had experienced stigma, where his grandmother showed ignorance of HIV and where there was conflict in the home between Zinzi and the grandmother. Zinzi had experienced AIDS-associated stigma in that she had lost friends who were concerned about contacting HIV from her, in her church when the minister declared that HIV was satanic and from a neighbour who thought that Ondela would infect her children. The grandmother ascribed blame to Zinzi and was fearful that others would think she was also HIV-infected. Arguments between Zinzi and her mother in the home about HIV/AIDS and overheard conversations between his peers, introduced Ondela to conflicting ideas about HIV.

5.5.2 Silence, stigma and shame

Zinzi felt Ondela was avoidant and Ondela believed that his mother did not wish to talk to him. Zinzi did not know what Ondela knew or felt about HIV/AIDS. Ondela and his mother have not had a meaningful conversation about HIV/AIDS or his mother's status. Zinzi stated she did not wish to disclose to Ondela herself because she thought that this would hurt him. However, Zinzi may have avoided disclosing to Ondela in an attempt to protect herself or to protect her own image of a mother in his eyes especially when she is held responsible for contracting HIV by the grandmother. Her actions indicate that when her role as a mother was threatened by her HIV status, she shifted her mothering responsibilities onto the grandmother. This was evident when the grandmother told Ondela about Zinzi's HIV status and when Zinzi explains her emotionally distant relationship with Ondela away in terms of

Ondela's preference for his grandmother. Zinzi is aware of Ondela's distress but she avoids dealing with it. She avoids talking to Ondela so that she can avoid confronting her own feelings about the consequences of her status for Ondela. Her experience of stigma in her home, church, community and the loss of her friends has had a profound impact on Zinzi as she spoke about her sense of loneliness and rejection based on her HIV infection. Zinzi does not wish to hurt Ondela, but underlying this fear is the reality that her HIV status will cause him harm, indirectly through the stigma he may experience in his association with her and directly through her death. Nagler et al. (1995) argue that the notion of HIV-infected parents bringing harm to their children is an additional and potent form of stigma that evokes or deepens shame and prohibits parents from talking to their children.

In circumstances where the information that is being withheld causes the secret-bearer mental and emotional distress, the child will experience that distress without a means to make sense of what is going on (Papp, 1993). Although Zinzi's HIV status was not a secret, Ondela's ignorance of HIV maintained by mother-child avoidance of the issue contributed to the distress he felt over aspects of maternal HIV infection that could not be avoided or hidden. Zinzi's symptoms of illness such as painful legs and fatigue were obvious to Ondela. Ondela's distress at his mother's illness, which he understood to be painful was not addressed or broached in the family. Furthermore, he had to make sense of his mother's distress in a home where his grandmother approaches HIV/AIDS with suspicion and fear. Arguments between his mother and grandmother were not hidden and indirectly communicated notions of HIV-infection as bad, dangerous and unacceptable by others. Ideas that portray his mother negatively are in conflict with the distress and pain that he observes HIV infection to cause his mother.

Wright & Nagy (1993) argue that family members' beliefs about a health problem is the problem. Ondela's view of his mother's HIV-infection is the problem. It is imbued with conflicting notions of his mother's pain and of unacceptability. Outside the home, Ondela is met with the same message as peers support the notion that HIV positive people must keep their status a secret. Ondela believes that people are frightened of AIDS and by association potentially frightened of him and his mother. His decision to keep his mother's status a secret protects him from expected rejection. He stated that children would not want to be friends with him if they knew of his mother's HIV status. Ondela is tainted by maternal HIV infection. In the absence of alternative and positive discourses about HIV/AIDS, particularly

from Zinzi, Ondela accepts the stigmatising view that he has been exposed to. The consequences are profound as Ondela seems to have accepted the notions that he is bad and a danger to others. In her silence, Zinzi has indirectly communicated her shame to Ondela and allowed him to be exposed to messages that repeatedly confirm his badness and her badness.

5.5.3 Communication and emotional support in the home

Direct communication with Ondela about HIV/AIDS did not occur and there was minimal emotional support to mediate his fearful beliefs. The absence of meaningful communication about illness and death is understood to be a significant vulnerability factor (Worden, 1996). In cases where the parent's illness is not acknowledged or spoken about, children know that something is wrong, however they are unable to speak about what is wrong (Nagler et al., 1995). The vulnerability engendered in Ondela was evident in his inability to talk about what he knew about HIV or his feelings about his mother's HIV-infection. For Ondela, HIV remained unknown and unexplained, its mystery further deepened by teacher's warnings that he should stay away from strangers, as they would give him HIV. Ondela could not talk about HIV/AIDS. He had no means with which to understand maternal illness and to mediate his experiences (Nagler et al. 1995). The context of Ondela's knowledge acquisition was poor and neglectful. He received vague, conflictual, indirect and decontextualised pieces of information that increased his confusion and anxiety. Most significant was that Ondela first heard from peers that his mother could die from AIDS, knowledge that he carried in silence and that was never discussed with his mother. The manner in which Ondela thought about and interpreted snippets of information gave rise to a number of unrealistic fears.

5.5.4 Misconceptions and meanings that engender vulnerability

Ondela was overwhelmingly worried. He knew that his mother was ill and he knew that HIV was painful, as he had witnessed his mother in pain. He also knew that HIV could be spread, but he did not know how. Without a means whereby he could make sense of his mother's illness, Ondela became increasingly anxious about the consequences of HIV-infection. Ondela's presentation was characterised by high levels of anxiety, tearfulness and confusion. Anxiety in the face of parental illness or loss manifests in many ways, but it can include anxiety over the child's sense of safety and over the parent's safety (Worden, 1996). Ondela worried that he could get HIV from his mother but he was unsure how this would happen. In addition, Ondela was concerned that he in turn would pass HIV onto others, and in this regard he becomes a danger to others. Ondela is isolated from his peers due to his need to

keep a part of his life a secret from them which impacts on his ability to become part of and gain acceptance in a peer group. Ondela's social development gains momentum in his adolescent years through which he should learn about the value of friendship, to experience and manage different points of view, gain opportunities to exercise independence and social skills (van Dyk, 2001). Instead, Ondela felt powerless and hopeless in terms of the future and in effecting any influence in his world.

5.6 Conclusions

According to Rutter (1988), in order to determine the impact of stressors on children, features in children's lives that may lead to difficulty with psychosocial adjustment should be examined with regard to underlying processes. In this study, the children revealed difficulties related to perceived stigma and expected rejection from others based on their mothers' HIV status and they showed concern over their mothers' anticipated deaths. The manner in which the children understood and managed these AIDS-associated stressors differed according to their unique contexts. Underlying family processes such as the lack of parental involvement in education about HIV/AIDS and emotional support for the children varied but were understood to play a central role in engendering vulnerability in the children. Parental involvement is seen to be an influential factor in offering protection or engendering vulnerability against stressors in childhood (Masten & Coatsworth, 1998; Worden, 1996).

AIDS-associated stigma on a community level, denial of or the experience of stigma in the home influenced the ability of the mothers to engage openly with their children around HIV/AIDS. The mothers avoided talking to their children and the children did not initiate discussions with their mothers. It was hypothesised that the mothers' own unresolved feelings about their HIV status and related feelings of shame, maintained avoidance and secrecy with their children. It seems as though shame was particularly pronounced with respect to their children, as both mothers to varying degrees were active counsellors or educators in the HIV/AIDS field. It may be that openness about their HIV status on all levels including transmission would make them vulnerable to their children's emotional responses. Funeka preferred that Thandi remain 'happy' and although Zinzi was aware of her son's distress in terms of his behaviour pre and post disclosure she did not engage with him on an emotional level. The mothers did not deny their status but they denied the impact that this had on their children. Nagler et al., (1995) assert that parents that are HIV-infected face the

challenge of acknowledging and coming to terms with the idea that their behaviour may harm their children.

Meaningful emotional support and clear communication were largely absent in a context where these processes could have played a central role in protecting the children from their own fearful fantasies. Instead, the children's beliefs about maternal HIV infection exacerbated their fear of HIV/AIDS. Thandi held misconceptions about the transmission of HIV and feared her mother's death, which remained unknown and uncertain. Ondela experienced overwhelming anxiety, feared that he would be infected and that both he and his mother would die a painful death. Both children feared being rejected by others because of their mothers' HIV status. Both children avoided talking about HIV in the home and with peers and remained isolated. Most significant, was that neither mother nor any adult knew what the children thought or what they felt. The mothers actively avoided finding out and the children learnt not to talk about 'it', to the extent that maternal HIV infection became a "nameless dread" in the families (Nagler et al., 1995). Mother and children may have wanted to talk to each other but they were both afraid of the consequences of this for their relationship.

5.7 Recommendations for Interventions

The findings of the present study will be used to highlight areas of intervention with AIDS-affected children and their HIV positive mothers. Suggestions made will be specific to mothers that are in the minor symptomatic phase of HIV infection and children aged between 10 and 12 or in the senior primary school years. A major finding of this study was that the mothers avoided HIV/AIDS related topics with their children. Although the mothers differed somewhat on how much was avoided, not talking about HIV in the family became accepted practice, so that the children were equally avoidant with their mothers. Silence between mother and child in the present study maintained emotional distance and an atmosphere of fear and mistrust, during a time when emotional support and openness can play an important protective function in mediating the impact of stressors associated with maternal HIV infection (Wild, 2001 and Worden, 1996). The broad aims of an intervention of this kind would be to bring mother and child together and thereby to encourage and facilitate communication. Fears around talking from both sides can be explored and the cycle of silence and secrecy broken. The process of achieving this will equip mothers and children to actively deal with difficulties around open communication, expression of emotion to each

other and the sense of isolation that secrecy maintained in the present study. As Ondela commented, "it is not right to keep secrets, people mustn't".

Support groups for children and separate concurrent support groups for mothers would form the basic forum for a time-limited intervention in three phases. The parallel treatment of mothers and their children has been used with young children that have been sexually abused (Damon & Waterman, 1986). For the purposes of making recommendations the broad structure and aims of an intervention providing support for both AIDS-affected children and their mothers concurrently, will be outlined in terms of the goals and proposed content of each phase.

In phase one, the groups will meet separately and then they will merge for phases two and three. Separate meetings initially, will allow each party to explore and express their own feelings and thoughts about talking to each other. The mothers in the present study hid aspects of their HIV infection from their children. Disclosure of their status through a third party or by the provision of facts alone, depersonalised this event and enabled the mothers to detach personal feelings such as shame from HIV infection. In doing so, the mothers could deny the changes that their HIV status would bring to their roles as mothers and to the relationships with their children. Mothers would need the space to acknowledge their fears and discomforts about talking openly with their children and the consequences of this for them would need to be broached and explored. The children in the present study had isolated themselves within their families and in their peer groups. Neither child wished to talk about maternal HIV infection because they feared being rejected on the basis of self-perceived and shameful difference from other children. Children may find it useful to explore their own feelings and thoughts about maternal HIV infection, to have their feelings validated and affirmed in a setting shared by children who are similar to them.

A major area of anxiety, confusion and distress for the children in the present study stemmed from the false beliefs they held about the transmission of HIV and the long-term consequences of this for them. One child worried that he would get HIV from his mother and that he in turn would pass HIV onto his friends. Frightening beliefs need to be identified and corrected. Phase one may include the provision of psychoeducation for mothers and children in response to false beliefs that emerge as each party talks about underlying feelings and beliefs that may be painful to acknowledge. In the present study, the mothers found it

difficult to admit to being vulnerable or to talk about issues such as conflicts in relationships and their response to HIV infection in a meaningful way. The use of play allowed the children to talk about their painful feelings and frightening beliefs as part of a gradual process within which trust and rapport could develop.

Two very important structures need to be in place in order to achieve self-reflection and expression within both support groups. Firstly, trained and skilled facilitators are required to encourage self-reflection and acknowledgement of fears, which in itself is a difficult and uncomfortable process. Care needs to be taken so that mothers and children are not left feeling exposed and vulnerable. Secondly, the development of trust and rapport between the facilitators and group members is essential to the creation of a safe, non-threatening and non-judgemental space in which deep and painful feelings such as shame and fear can emerge. The acknowledgement of and the expression of painful emotions can be approached gradually and indirectly. In this study, the use of play techniques was successful in this regard. However, play can be used with mothers too in the form of art-work and dramatisation. As van Dyk (2001) points out that the expression of emotion may take the form of song and dance rather than talk. Play techniques, especially those that require collaborative efforts such as puppet shows encourage story-telling through which the children's concerns and feelings can emerge. Within a group of children this may be an effective way of encouraging participation and team-work that leads to the development of friendship and common purpose. Art work and dramatisation would have similar effects in the group for mothers.

In phase two, mothers and children will meet together and the work done by each party independently will be presented to the other. This is an active phase of confronting painful feelings, sharing thoughts that may be difficult for the children or mothers to hear. It would also entail debunking previously held ideas and testing whether preconceived fears manifest as previously thought. Mothers and children as a group will have the opportunity to slowly tell each other what they had feared to in the past. For example, concerns can be introduced gradually and indirectly through presentation of puppet shows developed by the children and dramatisations or songs created by the mothers. Individual mother child-dyads will then have the opportunity to talk to each other about concerns particular to them.

Significant areas of concern identified by the children in this study related to unexpressed feelings of grief, concern with the anticipated death of mothers and worry about the future. In one case, the child was not able to talk about his fears around death with his mother or anyone else and he felt helpless and isolated. The reality is that AIDS-affected children will lose their mothers to death, which Worden (1996) argues is the most fundamental loss a child can experience. In this study, one child expressed feelings of sadness and worry when she anticipated her mother's death, both children were vigilant for signs that signified approaching death in their mothers such as physical illness and Thandi asked her mother about what would happen to her when she died. As channels of communication open up and trust is regained, children can look to their mothers to answer their questions and to explain areas of confusion. Most importantly, the children would be able to grieve and receive support in their relationship with their mothers. Mother-child dyads can explore active coping strategies that have meaning in their relationship and they can plan for the future together. Funeka had already made plans for the foster care of her children and had applied for foster care grants, which ensured a sense of future for Thandi. Other activities may be explored, for example, mother and child may want to set up opportunities for the children to participate more fully in decisions that will be made for their future and when appropriate about the funeral itself. Worden (1996) argues that encouraging children to participate in the decision-making process around parental illness and death allowed children a sense of importance and mastery.

During phase three, the skills learnt in phase one and two need to be practised and problems encountered dealt with. Ideally, skills learnt could be generalised to other areas in the members' lives. This is an important aspect of this intervention, as mother-child dyads in the present study had to cope with a number of other stressors in addition to HIV infection. In contexts where there are multiple stressors such as socio-economic difficulties, single-parent headed households or marital conflict, children's vulnerability increases with the cumulative impact of multiple stressors (Garmezy, 1988). During phase one and two, problems identified by the mothers and children will be unique to mother-child dyads as part of their contextualised lives. In phase three, mothers and children may want to use their skills to deal with other stressors such as stigma in their immediate community. Research has identified the insidious and powerful effects of AIDS-associated stigma in South Africa (Strobe & Barrett Grant, 2001) and this study has demonstrated how community censure contributed to feelings of shame in mothers and children. The ability to challenge negative community

perception and related self-perception is enhanced in supportive environments, which encourage active engagement with negative perceptions rather than avoidance or acceptance of these. Furthermore, mother-child dyads will be exposed to views and information that contradict the ignorance which usually fuels stigma (Strobe & Barrett Grant, 2001).

The support groups themselves would have established a support base for both mothers and children. Jewitt (2001) noted that children in the support groups she runs have learnt to use friendship as a coping mechanism. Besides bringing mothers and children together and opening up secrets, support groups have the added benefit of decreasing the children's and mothers' isolation wherein their experiences are normalised and accepted. Mother-child dyads can learn to identify, develop and use supportive resources available to them in their communities.

Practical considerations

Certain requirements need to be met in order to increase the success of the support groups and to ensure that the limited resources available are used effectively. Key theoretical and practical factors are discussed as follows:

- 1) Children who are at the same stage of development should be grouped together. This is very important because children at different ages have particular emotional, cognitive and social capacities and needs. Thus their orientation to maternal HIV infection will differ. Furthermore, expectations of their ability for self-reflection and expression of thoughts and feelings would be partly based on developmental maturity, which would then influence the format of the support groups.
- 2) Theoretical knowledge in the area of child development in adverse conditions and results from this study would form the theoretical foundation on which the intervention is based. In addition, active participation by the mother-child dyads will contextualise the theory so that the nature of concerns and problems and the options available to cope with these will be specific to group members' input. In this study, theoretical frameworks guided an inquiry that focused on the participant's frame of reference, so that problems and issues were relevant to their situated lives. Dawes & Donald (2000) argue that interventions in South Africa should be based on theory and they should use models and concepts that are meaningful to the target group (see section 1.2.8).

- 3) As a time limited and focused intervention, implementation could form part of already existing support group structures or HIV/AIDS initiatives and programmes in communities. Interventions that follow this model are sufficiently flexible to include children of different ages and can to be used for group or individual treatment. The structured and time limited nature of the treatment is useful in situations where resources are limited (Damon & Waterman, 1986).
- 4) To be effective the intervention would require commitment and continuity as it entails a process of growth for mother-child relationships with clear goals and intervening steps.

The suggestions for intervention outlined above are an attempt to provide much needed emotional support for AIDS-affected children by strengthening the relationship they have with their HIV positive mothers. Results of the present study show that the lack of maternal involvement in terms of offering the children HIV/AIDS-related education, guidance and emotional support was the key area engendering vulnerability in the children. Dawes & Donald (2000) state that interventions aimed at altering the proximal relationship between parent and child are most likely to succeed. It is further suggested that skills acquired by the children in the support groups such as communication skills, self-reflection, adaptive expression of emotions, empathic listening, identifying and making use of available supportive resources can stand them in good stead as they move forward into a future as orphans.

5.8 Evaluation of the study and implications for future research

An important feature of this study is the focus on the idiographic accounts of AIDS-affected children. The employment of case study methodology proved useful in generating case material that was unique and that reflected the children's meaning as they made sense of maternal HIV infection. The children's experiences could then be presented in their own terms as they gave voice to their needs and concerns. Understanding maternal HIV infection in this manner highlighted the role of personal meaning as a source of stress in itself. In this respect, the manner in which Thandi associated illness and hospitalisation with AIDS and death increased her vigilance around signs of illness in her mother where her appraisal was not congruent with objective reality of her mother's tiredness, feelings of stress and upcoming hospitalisation. Similarly, Ondela's association of HIV with uninformed ideas of

contagion increased his fear and anxiety over contracting HIV from his mother and then passing it onto his peers. This study has shown that the impact of maternal HIV-infection on AIDS-affected children cannot be understood solely with reference to their behaviour or expressed emotion such as sadness, worry and fear, but should take account of the psychological meaning that maternal HIV infection has for them.

The use of play techniques in the interviews with the children proved valuable in eliciting idiographic material around a sensitive topic. The children found it difficult to talk about their concerns with and beliefs about their mothers' HIV status. Play techniques such as puppet play in specific stimulus situations and drawings allowed the children to approach their perceptions and feelings gradually and indirectly, as they displaced and projected these onto characters in their stories. The use of puppets introduced an element of fun and humour during the interviews that helped to decrease anxiety and increased rapport between the researcher and the children. Play encouraged children to both introduce and explore issues, which limited the imposition of researcher bias, thereby increasing the phenomenological validity and the meaningfulness of the children's accounts.

Placing the children's accounts in the context of their everyday lives proved useful to developing an understanding of their unique experiences in terms of a wider set of influences and processes. Other sources of information such as interviews with the mothers, reading material given to Thandi such as the Soul City (1996) booklet and crime figures in Thandi's residential area offered alternate perspectives and objective evidence from which case material could be critically evaluated. It was apparent that the children and their mothers were faced with many stressors besides maternal HIV infection, such as socio-economic difficulties, marital conflict, lack of acceptance by family members and community AIDS-associated stigma. In addition, maternal HIV infection was not considered to be a single, bounded and simple stressor as the mothers imparted meaning to their status as they struggled to come to terms with HIV infection. This had an impact on their ability to openly communicate with and emotionally support their children.

Understanding the children's accounts in terms of their situated lives illustrated the complex interaction of individual, familial and community processes. In this regard, the influence of AIDS-associated stigma was apparent in feelings of shame in the mothers, specifically from their own sense that as mothers they would have brought harm to their children. The mothers

denied and attempted to protect themselves and their children from the changes that HIV infection would inevitably bring to their relationship. Avoidance and secrecy in the family maintained a cycle of silence and mistrust. Within this context, children remained isolated and were vulnerable to incorporating false beliefs and frightening fantasies into their understandings of HIV/AIDS as well as giving credence to negative and stigmatising community beliefs.

Shortcomings of the study are evident in the quality of the mother's accounts or the phenomenological validity of these. The degree to which the mothers' accounts reflected true perceptions and feelings may have been limited by the degree of trust and rapport developed in the interviews and by language differences. In addition, inferences about the role of the mothers' emotional and physical distress on their ability to parent would have been strengthened by data describing the nature of the historical relationship. Parenting capacity may have been a feature of general child-rearing practices and expectations. Future research in this area could explore the impact of HIV-infection on parenting capacity, specific to contexts in which many stressors are present.

Analysis of the case material led to a deeper understanding of the cases as they were compared and contrasted with other similar cases in the literature. In this manner case studies added to the case-law or theory on AIDS-affected children. However, the generalisability of the results of this study in these terms would be restricted to children aged between 10 and 12 and to mothers in the minor symptomatic phase of HI infection. In the minor symptomatic phase of HIV infection, most individuals show to varying degrees minor symptoms of illness and they are able to carry on with normal activities (van Dyk, 2001). Children aged between 10 and 12 or in the senior primary school years face a number of developmental challenges as children become more independent from their parents and engage socially with peers. Thus, the findings of this study would apply to the experiences of children at a specific developmental stage as they live with mothers in a specific phase of HIV infection. The experiences of children at different developmental stages living with mothers at different symptomatic phases may be different and particular to those interactions. Future research needs to investigate the impact of different dimensions of maternal HIV infection as a stressor and the influence this has on the experiences of children at different developmental levels.

With reference to the aim of the study, case material provided information about the lived contexts of AIDS-affected children. Their experiences were presented in their own terms as the children gave voice to their concerns and needs. Furthermore, the complexity of their experiences could be captured, as they were understood in terms of contextual processes occurring in the family and community. These processes and the issues raised by the two children illustrated how vulnerable the children are. They are fearful, confused, misinformed, mistrustful, alone and felt shamed as they attempted to cope with the reality of their mothers' anticipated death. Their mothers and communities overlooked these children's needs for emotional support while they held frightening ideas in silence. Nobody listened to the children who were too afraid to talk. When given an opportunity to talk as in this study, the voices of the children rang clear and loud. The children's stories powerfully show their need for support and for some-one to listen to what they feel and think and to heed their concerns. Geballe & Gruendel (1998, p.50) described all children affected or infected by HIV/AIDS as "the invisible childrenof AIDS". As it stands, AIDS-affected children are invisible to research efforts in South Africa that needs to focus on this group to support and develop intervention initiatives. Hopefully, as these children are encouraged to speak, they will be heard, given attention and supported.

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