

## Chapter 1

### General Introduction

Nearly a fifth of South African women of child bearing age were HIV positive in 2012 (Shisana et al., 2012). Fortunately, thanks to increased access to anti-retroviral treatment, the number of HIV related deaths have decreased (Statistics South Africa, 2012). As a result, infected mothers remain part of their children's lives for longer. Yet, notwithstanding the extended life expectancy, HIV heightens the mothers' vulnerability to illnesses, which impacts on their physical and psychological wellbeing, adding stress on the parent-child relationship (Lester et al., 2010). One such illness is HIV associated psychotic disorder, which affects an estimated 0.2 to 15% of HIV positive patients (Alvarez-Segura, Villero, Portugal, Mayoal, Montilla & Fraguas, 2008; Dolder, Patterson & Jeste, 2004). Due to the mothers' illnesses, parenting takes place in a high risk context with possible mitigating (e.g., social support) and exacerbating factors (e.g., stigma). However, this context has been largely uncharted in scientific research. An important aspect of parenting that is of particular interest in this study is the attachment relationship. Investigating attachment within the broader context of high risk as well as the availability of a support network may be important, because resilience factors such as social support could play a vital role through the attachment relationship between mothers and children.

### ***Research and theory pertaining to maternal HIV, psychosis, and mother-child attachment***

Psychotic disorder associated with HIV tends to surface when the illness has progressed to its later stages of development and is most likely to be diagnosed in people with a previous psychiatric history and those confronted with stressful life events (Alvarez et al., 2008; De Ronchi et al., 2006). Helleberg, Pederson, Pederson, Mortensen and Obel (2015) found that people living with HIV had a 7 times higher odds of developing acute psychosis compared to the normal population. The illness has a significant impact on a person's physical and psychological functioning. Gay and her colleagues (2011) studied people living

with HIV and psychiatric illnesses and they reported that the physical symptoms of sleep disturbances, fatigue, gastrointestinal pain and the accumulation of symptoms had a negative impact on their quality of life. Psychological dysfunction associated with HIV and psychosis includes symptoms such as hallucinations, poorly structured delusions that include thought insertion and -withdrawal, impaired attention and concentration, impoverished speech, limited insight, and a lack of cooperation towards those providing help (De Ronchi et al., 2006; McCombe, Auer, Maingat, Houston, Gill & Power, 2009; Nakasujja, Alleback, Agren, Musisi, & Katabira, 2012).

Physical and psychological disturbances associated with HIV and psychosis can be incapacitating to the individual. In addition, when the individual is a mother, her central role in the bioecological developmental context of her children suggests that parent-child relationships and family system functioning may mediate effects on children's development (Bronfenbrenner, 2004). In South Africa, young Black-African females between the ages of 30 and 34 years are most at risk for HIV (36% prevalence) and this is also the age when children are raised (Shisana et al., 2014; Statistics South Africa, 2012). When the mother is chronically ill with episodes of psychosis, she may struggle to fulfill the needs of her children as her own health takes priority (Murphy, Marelich, Armistead, Herbeck & Payne, 2010).

In households where the mother has HIV, the parent-child relationship becomes vulnerable to high levels of emotional distress, potentially leading to conflict and aggressive behaviour in the child (Lester et al., 2010). Murphy and her colleagues (2010) found that the mothers' anxiety about their ill health was associated with poorer parent-child communication and poorer parenting skills. The unpredictability caused by frequent hospitalizations together with the parents' inability to monitor their children can be disruptive for family stability and Murphy, Marelich, Herbeck and Payne (2009) reported an association with depressive

symptoms, anxiety and conduct disorder in the children. Mothers living with HIV reported mixed experiences of parenting. For some mothers the parental role was a motivator to survive (Wilson, 2007) while for others guilt and hopelessness about their situation dominated their experience of parenthood (Shambley-Ebron & Boyle, 2006).

Children of mothers with a diagnosis of psychosis are at risk as they are raised in an unpredictable, abnormal psychosocial environment. Malhotra, Kumar, and Verma (2015) found that these children scored significantly higher on externalizing and internalizing problems on the Child Behaviour Checklist (CBCL). Mothers with schizophrenia showed impaired abilities to recognize their children's affect, used odd or unusual speech when talking to their children, and they were less sensitive towards their children compared to normal controls (Healy, Lewin, Butler, Vaillancourt & Seth-Smith, 2015). The poor mother-child interaction of mothers with psychosis leads to children withdrawing from the mother, leaving them to deal with life's stresses on their own (Melle & Johansen, 2002; Wan, Salmon, Riordan, Appleby, Webb & Abel, 2007). Wan and Green (2009) predicted negative outcomes for parent-child relationships where the parent had schizophrenia, but it is unknown how psychosis in the context of HIV will influence the dyad's relationship.

When studying the parent-child relationship, attachment is highly relevant as a focus of such investigation. The theory specifically emphasizes the early conditions which may affect children's development of a sense of security with parental figures (Main, Hesse & Hesse, 2011). Attachment can be seen as an outcome of infants' evolutionary selected tendency to seek contact with a caregiver in times of need. The extent to which the caregiver is able to comprehend emotional signals and to sensitively respond to the infant's needs shapes the organization of the infant's attachment behaviour in the relationship with that caregiver, and influences expectations and behaviours in other relationships. The nature of

the interactions with the caregiver thus leads to an internal working model or mental representation of the relationship with the caregiver (Bowlby, 1969; Brown, Rodgers & Kapadia, 2008; Cassidy & Berlin, 1994; Stevenson-Hinde, 2007; Wilson, 2009), which carries the expectations and experiences regarding these interactions forward into future relationships.

Essentially attachment relationships can be classified as either secure or insecure (Ainsworth, 1985). According to Ainsworth (1985), children with secure attachment relationships may increase proximity with the caregiver through attachment behaviour such as crying if they sense danger in their vicinity; they expect the parent to respond appropriately. They are easily soothed by the caregiver and the attachment system will cede priority to other behavioural systems, such as the exploratory behaviour system. Ainsworth, Blehar, Waters, and Wall (1978) reported that infants in the secure group used their mothers as a secure base to explore from when they were in an unfamiliar environment and at home where they are familiar, they will spend longer times in exploratory play.

Insecure attachment relationships can further be characterized as organized or disorganized/disoriented/disordered (Cassidy & Marvin, 1992; Main, 1990, Main & Solomon, 1986; Main & Weston, 1982). Children classified in the organized categories utilize one of two possible strategies to maintain proximity to the unresponsive parent. Firstly, children may turn their attention away from the parent by showing little interest in the attachment figure and even avoiding contact (Ainsworth et al., 1978). They minimize attachment behaviour in comparison with the actual level of attachment activation in order to deal with the relatively rejecting mother (Main & Solomon, 1990). These deactivating strategies are used to deal with attachment insecurity and these children are classified as insecure avoidant (Ainsworth et al., 1978; Shaver & Mikulincer, 2004). Secondly, children who experience inconsistent caregiving from the parent demonstrate a preoccupation with the

parent as well as possible ambivalence towards the parent. They display heightened attention to the caregiver's whereabouts to ensure proximity to the caregiver and are classified as insecure ambivalent (Cassidy & Berlin, 1994; Ainsworth et al., 1978).

The attachment classification that is of particular interest in this study is the group classified as disorganized or disordered (the disordered group is a combination of the role-reversed controlling and insecure other groups as described by Cassidy and Marvin (1992) in the preschool assessment of attachment). This group was identified among infants by Main and Solomon (1986) and was described as infants who “exhibited a diverse array of inexplicable, odd, disorganized, disoriented, or overtly conflicting behaviours in the parent’s presence” (Main & Solomon, 1990, p. 122). It was hypothesised that many of these manifestations can be traced to frightening parental behaviour, as the child is frightened or threatened by his/her “safe haven” so that there is a “fright without solution” situation without the possibility of attentional and behavioural strategies to cope with stress (Main & Hesse, 2000; Hesse & Main, 1999). In infants a collapse of a possible behavioural strategy to cope with the activation of the attachment system is seen when parents are simultaneously the source of alarm and safety (Main & Hesse, 1990). Madigan and her colleagues (2006) concluded in their meta-analysis that there was an association between unresolved states of mind, atypical or anomalous parental behaviour, and disorganized attachment in infants.

The attachment relationship gradually develops in the early years to the phase where internal working models of the self and significant others start to form (Bowlby, 1973 as cited in Simpson & Belsky, 2008). The development of the child’s language and symbolic representations allows for more abstract and differentiated internal working models (Solomon, George, & De Jong, 1995). Children who are classified as disorganized during infancy presumably have an internal working model dominated by fear and helplessness,

which over time may lead into a behavioural strategy of controlling the caregivers through caregiving or punitive behaviour (Main & Cassidy, 1988; Jacobvitz & Hazen, 1999).

Children classified as insecure or disordered have a predisposition to be less self-reliant, have a poorer capacity for emotion regulation, and are less socially competent compared to secure children (Sroufe, 2005). Disordered classification in particular is associated with more externalizing problems such as anti-social and aggressive behaviours in children along with dissociation, impulse control and attention problems (Groh, Roisman, Van IJzendoorn, Bakermans-Kranenburg & Fearon, 2012, Sroufe, 2005). The long term effects of a disorganized classification in infancy was reported by Sroufe (2005) to reach at least into adolescence, increasing the likelihood of psychopathology in 17½ year olds. Children of mothers with HIV and psychosis are raised in a context with multiple stressors that originate from the mothers themselves (Wan et al., 2007) and therefore this group is hypothesized to be at a high risk for developing insecure and disordered attachments.

Support figures may play an important role in buffering some of the risks that children face when living with a mother who is HIV positive and diagnosed with a psychotic disorder. Sandelowski and Barroso (2003) reported that when mothers with HIV actively seek social support, their HIV-associated stressors lessened; active meaning-making coping enhanced and this in turn had a positive effect on their relationships with their children. Schatz and Ogunmefun (2007) found that in many instances the grandmothers played a very important role in supporting their children who were HIV positive and their grandchildren, as they were in many cases the only members of the family who received an income in the form of a pension. Deyr, Stein, Rice, and Rotheram-Borus (2012) also reported that positive social support for persons infected with HIV predicted more effective family functioning and less depressive symptoms.

Social support for mothers with psychotic illnesses is especially important as it lowers the risk for child maltreatment (Martin, Gardner, & Brooks-Gunn, 2012). Unfortunately, mothers diagnosed with psychosis tend to withdraw and experience relational difficulties with support figures leading to fewer supporters (Wan, Moulton, & Abel, 2008). The burden of support weighs down heavily in this group of supporters to mothers with psychosis as they are impacted physically, emotionally, and economically and as they have to cope with shame, embarrassment, guilt, and self-blame (Awad & Voruganti, 2008). It is not yet known how the combination with HIV will influence their experiences.

Therefore in this study, the researchers examined the linkages between HIV/AIDS, HIV/AIDS-psychoses, and parenting. Additionally the hypothesis was tested that preschool aged children from mothers with HIV and psychosis will have more insecure and disordered attachment compared to children from mothers with HIV only. The experiences of mothers with HIV and psychosis and their interactions with their children, the role of support figures such as family members in the upbringing of the child, and the needs of affected mothers and their support figures were investigated as well.

### ***Aims of the study***

The main aim of the study was to explore HIV/Aids related psychosis in South African mothers, mothers' experiences of the illness, as well as their relationships with their children, specifically their attachment relationships. We hypothesized that the distribution of attachment between children of mothers with HIV would be different from mothers with HIV and psychosis, particularly that the psychosis group would have more disordered attachment relationships. We further aimed to understand the mothers' experiences of their support networks as well as the support networks' experiences in assisting the affected mothers and children.

HIV related psychosis is a neglected topic in research and specifically in the context of parenting (Shisana et al., 2014), therefore the first task was to examine the existing literature and integrate the fragmented findings to chart links between HIV/Aids, psychosis, and parenting (Chapter 2). This study viewed parenting in terms of the mother-child relationship and the larger support network. The second task of the study was to examine the experiences of mothers with HIV and psychosis with regards to their illness, their role as caregivers, their interactions with their children, as well as their perceptions of their support networks compared to the support networks of mothers with HIV without psychosis (Chapters 3, 4, and 5).

An aspect of the mother-child relationship that was of particular interest was the attachment relationship (Chapter 4). Here we aimed to assess the difference in the distribution of attachment patterns among the preschool aged children of mothers with HIV versus HIV related psychosis. We tested the hypothesis that children from the HIV and psychosis group would have higher rates of disordered attachment compared to children of mothers who only had a diagnosis of HIV. In addition the associations between socio-economic risks and attachment and emotional support and attachment were investigated. The distribution of attachment of our sample was also compared to other studies from normal and at risk populations.

As the support network was an important theme in this study, the role, needs and challenges of relatives who formed part of the support network of mothers with HIV and HIV related psychosis were explored (Chapter 5). Lastly, as this study benefited from the data collected from the affected communities, it was important to provide added value by means of psycho-educational outreach through disseminating results in two articles published in popular magazines that are distributed at HIV testing centres in South Africa (Appendix).

## ***Research approach***

This study had a cross sectional research design in which study participants reported on their internal states of mind at a single point in time and reports of retrospective experiences as well as current behaviours were collected (Lindell & Whitney, 2001). A multimethod approach was used in this study based on the research questions asked. This allowed for a broader scope of study, taking conceptual aspects of the phenomenon into consideration (Esteves & Pastor, 2004). As a result, multiple methods were needed to investigate individual aspects of the mothers' experiences, the mother-child relationship, the mothers-child attachment relationship, and the support experiences from both mothers and support figures.

Mothers with HIV and/or psychosis, their children, and when possible a support figure participated in the study. The 86 mothers were recruited into two groups, namely mothers with HIV ( $n = 41$ ) and mothers with HIV and a diagnosis of a psychotic disorder ( $n = 45$ ). This enabled isolation of the additional factor of psychosis in relation to various aspects of their illness experiences, support networks, and their attachment relationships with their children. In total 86 children from the mothers between the ages of 2 and 9 years participated in the study. All the mothers were asked to invite a family member who they viewed as an important support figure to participate. A total of 33 relatives were interviewed.

An initial step of the study consisted of a systematic literature review on the interrelationships between HIV/AIDS, psychosis, and parenting (Chapter 2). The researchers systematically sifted through 4370 articles to select a total of 50 relevant articles that were critically appraised and synthesized. During the data collection with participants a mixed methods approach was used and participating mothers completed the Community Assessment of Psychic Experiences (CAPE) (Konings, Bak, Hanssen, Van Os, & Krabbendam, 2006) to

assess the presence of positive, negative, and depression-related symptoms of psychosis in both groups of mothers. Thereafter they participated in semi-structured interviews about their experiences of their illness, their relationships, and interactions with their children, as well as their support networks. Mothers also completed the Support Interview Guide (SIG) (Llewellyn & McConnell, 1999) in interview format to assess the composition, structure, and functionality of support networks (Chapter 3).

To compare the attachment relationships of the two groups (HIV with or without psychosis), the Strange Situation Procedure (SSP) (Ainsworth, Blehar, Waters, & Wall, 1978) was administered (Chapter 4). Video recordings were translated and subtitles added for independent, trained coders to code the videos using the MacArthur Preschool Attachment Coding System (Cassidy & Marvin, 1992). This part of the study was quantitative. A qualitative approach was used to interview family members about their experiences of the mothers' illnesses, their role as supporters to the mothers and caregivers to the mothers' children, as well as their needs and challenges in this regard (Chapter 5). Lastly, results from the study were disseminated via articles that were written for popular magazines that are distributed at all HIV/Aids testing centres in South Africa (Appendix).

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