

Chapter 3

HIV/Aids and psychosis: needs, challenges and support of affected mothers

Spies, R., Sterkenburg, P.S., Van Rensburg, E., & Schuengel, C.

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Abstract

Little is known about parenting in the context of HIV and psychosis, a co-existing condition affecting many mothers in South Africa. This study uses a mixed methods approach to firstly, qualitatively investigate the illness- and parenting experiences of a case group of mothers with HIV/Aids and psychosis ($n = 41$). Secondly, the support networks of this group is compared with a control group of mothers with HIV/Aids without psychosis ($n = 44$). Integrating qualitative and quantitative data highlights the emotional and physical disruption experienced by the case group, contributing to dysfunctional mother-child interactions. This may be detrimental for the child's well-being and attachment relationships. Healthy support networks may buffer these adversities. The availability of support figures was similar between the groups, but the case group had less spousal support. Paranoia associated with the case group predicted fewer support figures emphasizing the vulnerability of this group of mothers and children.

The combination of HIV/Aids and psychotic problems may affect multiple life domains including support in the parenting role. Between 0.2 to 15% of people diagnosed with HIV may develop a psychotic illness associated with or exacerbated by HIV (Alvarez-Segura et al., 2008; Dolder, Patterson, & Jeste, 2004). Given the prevalence of HIV/Aids in young women in Sub-Saharan Africa (42.6% for females between 30 and 34 years; Global AIDS Response progress report 2012), HIV related psychotic illness may be an important but ill-understood epidemic. These problems extend not only to the young women themselves, but in this demographic group also their children (Papalia & Feldman, 2012). The combination of having a diagnosis of HIV, a psychotic illness, and being a caregiver to a young child may create unique challenges and needs. All mothers need a functional support network, especially under stressful conditions. Given the stigma and nature of the diseases of HIV/AIDS and psychosis, social support is not self-evident. It is therefore of great importance to examine parenting challenges and burdens of mothers with HIV-related psychosis and the manner in which they engage with their support networks.

A diagnosis of HIV/Aids may have different outcomes for parenting being either constructive or destructive depending on the individual contexts (Spies, Sterkenburg, Schuengel & Van Rensburg, 2013). For mothers with HIV/Aids, parenthood can be a motivator to take responsibility for their health in an attempt to prolong the time spent with their children (Wilson, 2007), but it can also lead to feelings of guilt and impotence when they face the possibility of their children being orphaned (Shambley-Ebron & Boyle, 2006). Similarly there are also constructive and destructive outcomes for children in the context of the parent-child relationship. When a good quality parent-child relationship exists, it can create a buffer against depressive symptoms in children (McKee et al., 2007). When a bad quality parent-child relationship exists, Lester et al. (2010) found that adolescent children of mothers diagnosed with HIV were more aggressive during parent-child conflicts and family

functioning was more impaired because of maternal emotional distress, when compared to a neighbourhood control group of HIV- mothers in an African American sample.

Most available literature on parent-child relationships of parents who have a psychotic illness is based on schizophrenia research. There is similarity in the clinical picture of schizophrenia and HIV-associated psychotic disorder (De Ronchi et al., 2006). Wan, Moulton, and Abel (2008a) reported that mothers with schizophrenia had poor mentalization and that they were less empathic towards their children. Schizophrenic mothers were also less sensitive and less responsive towards their children's needs than mothers with bipolar disorders and depressive disorders (Wan, Warren, Salmon, & Abel, 2008). Mothers with schizophrenia also had negative responses to children's positive behaviour and these children tended to be more avoidant of their mothers (Wan, Penketh, Salmon, & Abel, 2008; Wan et al., 2007).

HIV is seen as a chronic illness (Tedlie Moskowitz & Wrubel, 2005) and according to a meta-analysis by Sieh, Meijer, Oort, Visser-Meily, and Van der Leij (2010) chronic illnesses in parents are associated with a number of negative outcomes for their children, such as a significantly increased display of internalizing problem behaviour compared to children of healthy parents. When HIV positive mothers have an additional mental illness, high demands are placed on their already vulnerable contexts and support may be a high priority. The importance of parenting support for mothers with severe mental illnesses such as psychotic disorders is emphasized by David, Styron, and Davidson (2011) who argue that these mothers have additional needs and therefore need to rely more on support than mothers without mental illnesses

According to Sandelowski and Barrosso (2003), motherhood encourages HIV+ women to seek social support and this in turn lessened their HIV-associated stressors and

enhanced active meaning-making coping that improves the quality of their relationships with their children. In contrast, mothers with psychotic illnesses tended to withdraw, and experienced more relationship difficulties that lead to a smaller chance of having a partner as part of their support network (Wan, Moulton, & Abel, 2008). Mothers with psychotic illnesses are often aware of their needs for parenting- and social support, but they are distrusting and hostile towards those offering support (Jungbauer, Stelling, Kuhn, & Lenz, 2010). The needs of mothers with HIV and psychosis may thus be different from mothers with HIV only, but to date this high risk group has not been well studied (Spies et al., 2013).

The first aim of this study was to examine how the symptoms of HIV associated psychosis are experienced by South African mothers with regards to their role as caregivers and how these experiences are manifested in the interactions with their children. The second aim was to describe the experiences by mothers with HIV and psychosis with their support figures, using a mixed methods design. To discover the distinct needs associated with the combination of HIV and psychosis, cases were compared to mothers with HIV without psychosis.

Methods

Design

A mixed methods approach was applied, examining the experiences of a group of mothers with HIV and psychotic problems, lending towards a qualitative inquiry as the focus was to understand the contexts of these mothers (Creswell & Plano Clarke, 2007). The addition of a quantitative measurement firstly compliments the findings of the qualitative data, by elaborating in a structured manner on the experiences of these mothers with their support figures. Secondly it triangulates a portion of the data through integrative analysis, as

the support network of this group of mothers was compared with that of a group of mothers with HIV alone (Boeije, Slagt, & van Wesel, 2013).

Participants and procedures

Participants were recruited using convenience sampling. Clinicians invited participants who were diagnosed with HIV at one of the three hospitals and seven clinics that participated in the study. All the mothers in the sample were previously diagnosed with HIV at a hospital or clinic. HIV testing and counselling (HCT) staff from the health care facilities conducted the tests for HIV and based a diagnosis of HIV on a reactive rapid test and also once a confirmatory rapid or Enzyme Linked Immunosorbent Assay (ELISA) test was positive. All participants received pre- and post-test counselling before recruitment for the study. Two hundred and twenty seven mothers with children between the ages of 2 and 8 years old were invited to participate in the study. Informed consent was given by 85 mothers (case group: 44 mothers with HIV and psychoses, and comparison group: 41 mothers with HIV without psychoses). The mothers with HIV and psychoses (HIV+P) between the ages of 20 and 49 ($M = 33.4$, $SD = 6.4$) were recruited from 3 psychiatric hospitals in Johannesburg, Potchefstroom, and Madadeni in South Africa. The mothers were selected based on a diagnosis of HIV associated psychotic disorder according to the DSM-IV-TR (Association, 2000). A diagnosis of HIV was made as reported above and the diagnosis of psychosis was made by a multidisciplinary team consisting of at least a psychiatrist, clinical psychologist and nursing staff. Medical doctors invited these mothers to take part in the research if they were outpatients of the hospitals and their mental illness was in remission. Forty-one HIV+ mothers without psychosis (HIV-P) between the ages of 22 and 46 ($M = 33.5$, $SD = 6.4$) were recruited in a similar manner from 7 clinics in Potchefstroom for the comparison group. The mothers from the case group were asked to participate in the qualitative segment of the study and a sample of 24 mothers consented to participation. The sample consisted of Black South

African women with low incomes (94% reported periods of time when they did not have food in their houses because of financial difficulties) and a low level of education (77% did not complete school, with 19% having only primary level schooling). General information from the demographic questionnaire indicated no significant differences between the two groups for general background variables such as age, number of children, financial problems, mother using alcohol or drugs, father using alcohol or drugs, the level of education of mother and of father, experiencing conflict in the environment and having an occupation. The demographic characteristics are presented in Table 1.

Participants were given an incentive of a R100 gift card (€7) and transportation and meals were provided. The research team consisted of 3 researchers who were of a different ethnicity and language than the participants. For this reason they were assisted by 5 translators who shared similar demographics with the participants.

Table 1 *Demographic characteristics of mothers in the sample (N = 85)*

Categories	Total sample	HIV mothers without psychosis	HIV mothers with psychosis
Age mother (<i>M, SD</i>)	33.5 (6.4)	33.49 (6.38)	33.41 (6.42)
Age child (<i>M, SD</i>)	5.1 (1.9)	4.93 (1.87)	5.17 (1.96)
Number of siblings (<i>M, SD</i>)	1.4 (1.1)	1.34 (1.26)	1.48 (1.02)
<i>Highest level of education (n,%)</i>			
≤ Primary completed	16 (18.8)	9 (22)	7 (15.9)
Some secondary completed	49 (57.6)	24 (58.5)	25 (56.8)
≥ Secondary completed	20 (23.5)	8 (19.5)	12 (27.3)
Occupation (<i>n, %</i>)	5 (17.6)	11 (29.7)	4 (14.8)
<i>Town (n, %)</i>			
Potchefstroom	48 (56.5)	39 (95.1)	9 (20.5)
Klerksdorp	2 (2.4)	0 (0)	2 (4.5)
Stilfontein	6 (7.1)	1 (2.4)	5 (11.4)
Newcastle	1 (1.2)	0 (0)	1 (2.3)
Johannesburg	26 (30.6)	0 (0)	26 (59.1)
other	2 (2.4)	1 (2.4)	1 (2.3)
Single parent (<i>n, %</i>)	62 (72.9)	24 (58.5)	38 (86.4)
Financial problems (<i>n, %</i>)	80 (94.1)	39 (95)	41 (93)
Financial support from father (<i>n, %</i>)	28 (32.9)	18 (44)	10 (23)

M = mean, SD = standard deviation, n = number and % = percentage

Qualitative analysis

Semi-structured interviews were conducted with the aim of eliciting in-depth narratives from participants. The interviews focused on the mother's experiences and perception of her illness, her interactions with her children, needs and challenges related to being a caregiver, and the role of support figures in her life. Interviews were conducted with the help of translators who then transcribed and translated the audio recordings to English. An inductive and step-by-step approach was followed as described by Braun and Clarke (2006).

In order to become familiar with the data, the first and third author read and re-read the interviews attempting to immerse themselves in the participants' contexts, looking for patterns and meaning in the dialogue. Codes were then generated based on the initial research questions and then sorted into potential themes and subthemes using mind-maps. These themes were then evaluated for internal homogeneity and external heterogeneity (Patton, 1990) before being finalized. The process of becoming familiar with the data, identifying patterns, and constructing themes commits the researchers to a deeper level of engagement with these mothers and the contexts in which they function.

Quantitative analysis

The main aim of the quantitative analysis was to assess the participants' support networks with regards to their composition, amount of support figures, how these were structured, and the functionality of the networks. For this purpose the Support Interview Guide (SIG; Llewellyn & McConnell 1999) was used in an adapted form and translated to Setswana and IsiZulu by accredited translators from the South African Translators Institute (SATI). This is a semi-structured interview that creates a list of participants' support figures and then categorises those support figures in an interactive manner. The instrument was

originally designed to assess the nature of support of people with learning difficulties, but was chosen for this specific population as it requires limited literacy skills from participants who have little or no formal schooling.

The Community Assessment of Psychic Experiences (CAPE) was used to identify participants from the group recruited as mothers with HIV without psychosis who may report significant levels of psychosis. These mothers were then excluded from the study. Good validity and reliability has been proven for the instrument for screening for the presence of positive and negative symptoms of psychosis (Konings, Bak, Hanssen, van Os, & Krabbendam, 2006). Stefanis and colleagues (2004) performed a principal component analysis as well as a varimax rotation in order to identify symptom clusters on the positive experiences spectrum of the CAPE. The four identified factors included paranoia, first rank, hallucinatory and grandiose experiences. These four factors were taken into consideration in this study.

Quantitative data were analyzed using SPSS version 21. In order to assess the difference in support network composition, frequency of contact and access to support figures between the two groups (HIV with or without psychosis), t-tests, Pearson correlation coefficients and logistic regressions were performed.

The North-West University Ethics Committee, North-West-, KwaZulu Natal- and Gauteng Provincial Departments of Health gave ethical approval for this study. Participants were informed of the nature of the study and gave written consent for participation. Ethical guidelines were adhered to as prescribed by the Health Professions Council of South Africa and the American Psychological Association.

Results

Qualitative results

An analysis of the interviews with the mothers with HIV and a psychotic illness generated a number of codes that crystalized into subthemes and can be divided into three broad themes. First, to get an indication of the participants' understanding and experiences of their illnesses, the themes related to this aspect are reported.

Mother's understanding and experiences of the illness

Most of the participants described having been treated for a mental illness and that they had some understanding of a relationship with HIV, such as the mother who reported that *"being HIV+ affects you and your mind just goes."* They frequently related the stressors of HIV with the onset of abnormal experiences as a mother reported, *"Stressing can change your behaviour... I had lots of stress, so I was hearing voices and the TV was talking to me; that was not normal."* During the recruitment participants were informed of the topic of the study, however a number of mothers did not acknowledge their illnesses, whether HIV or psychosis. One mother described, *"...they said that I am mentally ill, but I don't see it,"* while another admitted having a mental illness, but not any other medical diagnosis. Culture and belief systems played a role in some participants' understanding of the root of their behaviour and in certain instances it was seen as a blessing or a gift from God or the ancestors. A mother from Potchefstroom explained that, *"I was wondering if it is God communicating with me or maybe my ancestors talking to me, because I have heard that they exist."*

Having a diagnosis of HIV and a psychotic illness placed the mothers in a very vulnerable situation where psychological and physical well-being was compromised. The mother has to deal with the hardships of physical pain and declining bodily functions. A

participant reported: *"I would feel tense and heavy headed,"* and another one said, *"I told my friend that I have a stiff neck and I lost a lot of weight."* A mother from Potchefstroom was very emotional when she explained, *"I couldn't see, I was blind for two months. I am still blind in one eye and I was paralyzed, I couldn't pick myself up."*

Various participants spoke of a looming fear of death and believing that they will not recover: A mother explained, *"I thought that I won't recover... When the illness came, I just wanted to live."* Another participant reported that *"I heard a voice asking if I can see the graves. After the voice I saw the tombstones and I went into the house and I heard the voices saying I am going to die."* One mother related her experiences at the clinic where she was given the diagnosis, *"When they told me the news, I thought I was going to die right now."*

Adding to these physical concerns, the distressing experiences of a severe mental illness created additional burdens that exacerbate the mother's situation. Participants generally provided anecdotes that they can recall prior to their admissions to hospitals and a few reported witnesses' accounts of their behaviour. Half of the sample reported examples of being angry or aggressive. Two of the mothers narrated especially dangerous behaviour. One mother reported, *"I fought with everyone in the house. I had sleepless nights and I would wake up around 4am shouting at my children... I almost burnt them in the house with paraffin."* A second mother said, *"Every time I got too angry... I didn't want them (children) near me when I'm ill. I felt that I was going to hurt them. I get too angry and then I break things in the house. I broke a sofa. I lifted it and threw it at my mother."* Another abundant theme relating to mental illness was the experience of distressing sounds or noises, particularly voices threatening the participant. A mother from Johannesburg reported, *"I heard people insulting me, but I couldn't see them. Sometimes it will be like someone is sitting next to me talking to me or fighting me and I will take a broom and fight back."*

Confusion and behaving in a manner that was seen by others as inappropriate was often reported. Participants talked about times when they were disorientated and not aware of what was going on around them. They were behaving in ways that may endanger them, lead to a loss of dignity or elicit negative feedback. A mother reported *"running into the street and then kissing the ground,"* while another was *"pulling on the wires of an electricity box."* Difficulty in recalling certain events was reported by some and may be attributed to the illness, or the effects of sedation in hospital.

Fostering distressing beliefs and experiencing fear interfered with their daily lives as some mothers' behaviours were affected by their beliefs. One participant remembered an exceptionally distressing belief where she was convinced that her friend killed and ate her sister's child, she said, *"I went to my friend's home, looking for her, but I couldn't find her. My mind told me that she was under the bed, I kept looking for her under the bed and throwing the bed with stones."*

Additional challenges associated with or exacerbating HIV and psychosis, coloured the mothers' contexts. The most prevalent subtheme relates to financial difficulties that make it more difficult to survive and provide the basic needs for the mothers and their children. It will increase the mother's level of distress, having negative consequences for her mental health. One mother reported, *"...they want to eat and sometimes there is no food in the house and she will say that she is hungry and I will start stressing."*

A subtheme relating to the mothers' experience of her illness concerns their emotional pain. The majority of mothers experienced feelings of anxiety, sadness, and guilt. The diagnosis of HIV was more at the foreground than the diagnosis of a mental illness as they talked about their feelings. The despair and guilt were particularly evident in one mother saying, *"Until I was discharged, I would not want to take my treatment, because at*

times I felt like I was not worth it." There were a couple of mothers who thought about suicide and one mother even admitted an attempt: *"...I decided to commit suicide, so I drank a bottle of brake fluid. I didn't want to tell anybody about my diagnosis, not even my mother."*

Coping with HIV and mental illness was the last subtheme identified in the interviews with the mothers. A coping mechanism for some of the mothers was to convince themselves that they have to appear fine, especially for the sake of their children as a participant explained, *"every time they are around, I pretend to be well."* Another participant said: *"You know what, I see myself living like other people who don't have HIV. Life is OK just like before I found out I was sick. Life is OK, life is OK, life is OK."* Secondly, it was important for mothers to set future goals, especially related to their children as described by a participant: *"I am a hard working person, so I want to go back to school and work hard for my daughter."*

Mother-child interaction

The theme on the mother-child interaction can be divided into two subthemes, namely the mother's experiences and reactions towards her child and the child's experiences and reactions from the mother's perspective.

Maternal mental illness had negative repercussions for the interactions with their children as many mothers reported aggression towards their children. A mother reported, *"...I spent most of the time focusing on my illness; the voices commanded everything, I didn't have time for my kids and it was even worse... my older child was making something and then I beat him."* The preoccupation with the distressing experiences also led to some mothers rejecting their children and the children were not a priority as described by one participant: *"I didn't want them near me when I was ill... I felt that I was going to hurt them..."*

I get upset and break things in the house... He becomes upset when he wants to play with me and I don't feel like it. He then goes out and cries." In times of sickness it was more difficult for participants to fulfil their parenting roles and a third of the mothers disclosed that they had an insufficient capacity to provide the basic needs of their children. A mother described, *"I didn't have time to feed her, bath, cook and do her laundry. I wasn't even thinking about my kids."* Some mothers recalled times when their children formed part of their distressing experiences, and one mother said, *"I saw him upside down as if his head was on his feet and his feet were on his head. It was very painful."*

Participants highlighted their children's interactions with them during the times that they experienced mental illness. More than half of the mothers reported that their children feared them during the time of their illness, with some mothers also reporting avoidant behaviour from their children after having been stabilized, such as the mother who reported, *"This one was very scared of me. Really scared of me, he had forgotten me... I stayed over two months in hospital and he was one (years old)... He didn't want me to touch him. He didn't want me near him."*

Some of the children were concerned about the mothers and even assuming a caregiver role as a mother stated, *"...when I start saying that I am sick, she will not want to play... I will forget to take my tablets and she will say: 'Mommy, you didn't drink your tablets.'"*

Mothers' experiences of their support networks

Of all the identified themes, the theme most frequently reported by participants was the value that they placed on having a supportive mother themselves. In times of illness, the participant's mother was her pillar of strength that she can rely on to take over the caregiving responsibilities of her children. A few participants still relied on their mothers to help them

with their children even after having been stabilized, as a mother from Soweto reported, *"She (mother) still does everything for them, laundry, cooking and bathing and helping them with school work."*

Husbands and partners featured during discussions about support and a few mothers experienced them as emotionally supportive, but more often they reported a lack of support from their spouses as this participant explained, *"After disclosing to the father of my child, he dumped me. I found someone else but he also dumped me after he found out about my (HIV) status."* Other support figures mostly included female relatives such as sisters, aunts and cousins. They would often support them with the caregiving of the children; provide emotional support and sometimes also financial support. The mothers generally placed a high premium on their support figures as illustrated in the statement by this mother: *"If my sister didn't help me, I would have killed myself by now. Even though I don't want to do it, I think I would have taken my life."*

Participants from this study viewed the supporting role of professionals predominantly for the provision of medical treatment. Emphasis was placed on the importance of using medication and only one participant talked about the emotional support that she received from a psychologist.

Stigma about being HIV+ was a stressor that participants had to deal with and it affected the support that they received from others. It was reported that people tend to keep their distance if they knew about the mother's HIV status: *"You know when you are positive, people they... they don't want to eat your food, they don't want to touch anything you touch."* None of the participants mentioned stigma experienced because of mental illness.

Quantitative results

Results for the SIG indicated that the 85 mothers reported a total of 490 support figures. Mothers from both groups identified on average 6 persons in their networks and mothers with HIV without psychosis had a mean of 6 (SD=3.4) support figures and mothers with HIV and psychosis a mean of 5.6 (SD=2.5). Differences in size or composition of the networks between the two groups were not statistically significant. Family members formed the largest part of the support network, followed by other members in the household, friends, neighbours and then professionals in diminishing order.

Paired samples T-tests were conducted to compare the type of support received by mothers with HIV with and without psychosis in the SIG. Results are presented in Table 2. There were no statistical significant differences found between the two groups, with all the mothers receiving mostly emotional support, then practical support, followed by companionship support and lastly information support. Both groups reported having more support figures with which they have reciprocally supportive relationships, thus giving and receiving support from their support figures. There were no statistical significant differences between the 2 groups (HIV with and without psychosis) in terms of reciprocity of the support relationship.

When narrowing down the household dimension and only focusing on spousal support there was a medium negative correlation with psychosis ($r = -.39$, $N = 85$, $p < .001$). A logistic regression was done in order to determine whether the presence of psychosis predicted the chance of having a spouse as a source of support for the mother. The model was significant, $X^2(1, N = 85) = 13.3$, $p < .001$, indicating that mothers with HIV and psychosis were less likely to receive support from a spouse than mothers with HIV only.

The responses on the CAPE (Stefanis et al., 2004) indicated that mothers with higher paranoia factor had smaller support networks ($r = -.26, N = 85, p < .001$). Mothers reporting higher levels of paranoia also reported less dependence on support figures ($r = -.22, N = 85, p < .001$). No other associations were found between psychotic characteristics and support.

Table 2 *Group comparisons of support networks*

Categories	HIV mothers without psychosis	HIV mothers with psychosis
<i>Type of support received by mothers (M, SD):</i>		
Emotional support	3.7 (2.4)	3 (1.5)
Practical support	2.9 (2.2)	3 (1.9)
Companionship support	2.3 (1.7)	2.1 (1.7)
Information support	2 (1.7)	2 (1.6)
<i>Reciprocity of supportive relationship (M, SD):</i>		
Reciprocally supportive relationship	4.2 (2.7)	3.3 (2.1)

M = mean, SD = standard deviation

Discussion

The experiences of mothers with HIV associated psychosis in the contexts of childrearing and the interactions with their support figures was studied using a mixed methods approach. In order to optimise the investigation, multiple dimensions of examination were used in this study and in the process trustworthiness of the findings was increased and meaning was added. An integration of the qualitative and quantitative findings narrates the

harrowing experiences of the mothers with HIV associated psychosis. It is contrasted with the rather similar availability of support figures, except for spouses. The quantitative data emphasizes the role of florid paranoia in their access to the support network. Comparing the two groups, mothers with HIV and mothers with HIV and psychosis, allows the researchers to identify the unique support challenges experienced by the mothers with HIV and psychosis. The addition of a comparison with mothers living with psychosis only, could yield further information about the role played by the presence of HIV, yet the current findings sufficiently demonstrate the disadvantages associated with living with HIV and psychosis.

HIV associated psychosis in mothers may result in aggressive and rejecting behaviour towards their children and an inability to fulfil their parenting role adequately. This is due to the mothers experiencing physical and psychological pain because of the symptoms of the illness and it leads to the child's physical and emotional needs not being met. It is worsened by factors such as a fear of death and poor understanding of the illness. During interactions with their children; children react towards their mothers with fear and avoidance and some children take on a caregiving role towards the mothers.

Mothers with HIV associated psychosis thus need extra support to help them cope with their own physical and psychological burden and also to help them with the parenting of their children. Like mothers with HIV without psychosis, mothers with HIV associated psychosis mostly rely on their family members for support and in particular their own mothers. Most mothers with HIV associated psychosis do not experience their spouses as supportive and were less likely to have a spouse in their support network compared to mothers with HIV without psychosis. Mothers with HIV associated psychosis who were more paranoid also had less support in general. Financial problems and stigma have a negative effect on support. The complexity of this dual diagnosis of HIV and psychosis necessitates a

larger role from professional support figures, yet they make up the smallest part of the support network for these mothers.

The experience of mothers with HIV associated psychosis needs to be viewed as part of a larger setting in which other challenges interact with their illness experiences. From the demographic particulars interview, unemployment, poverty, limited access to resources, and dangerous social environments were highlighted, and in combination with physical illness, hallucinations, confusion, high risk behaviour, and emotional distress, possibly creating a context that may be disempowering for these women. Lagan, Knights, Barton, and Boyce (2009), Montgomery (2005), and Carpenter-Song, Hocombe, Torrey, Hipolito, and Peterson (2014) reported similar findings of mental illnesses interacting with psychosocial contexts in their studies on mothers with mental illnesses. Carpenter-Song et al. (2014) found that this is especially true in non-Western cultures where illness narratives are embedded in the socio-economic backdrop.

The majority of participants from this study reported intense emotional distress relating to various aspects of their contexts, including anxiety about physical and psychiatric symptoms, guilt and sadness, as well as thoughts of suicide. De Ronchi et al. (2006) reported that people with first episode HIV related psychosis had less affective symptoms than people with first episode schizophrenia. This finding was not tested in this study, but the narratives of mothers with HIV associated psychosis indicate a strong presence of affective symptoms which can be interpreted as outcomes of their diagnosis in their contexts. Emotional distress because of the HIV diagnosis, stigmatization and declining health was reported and is echoed in other South African studies on women's experiences of having HIV (Hosegood, Preston-Whyte, Busza, Moitse, & Timaeus, 2007).

Disturbances in mother-child interactions of mothers with HIV associated psychosis were clear in the narratives of the participants. Themes of aggression, rejection, and neglect were prominent and can be considered severe when compared to the behaviour reported about mothers with schizophrenia in other studies (Spies et al., 2013). Wan and others (2007) reported that schizophrenic mothers had low sensitive responsiveness towards their children, which is similar to the reports of the mothers in this sample who testified that they were so preoccupied by their illnesses that their children were not a priority. This leads to the children's basic needs not being met. Unprovoked aggression and rejection towards the child, even when the child was playing alone, was narrated and was similar to the negative responses of schizophrenic mothers in the context of positive behaviour of their children (Wan et al., 2008).

These behaviours are unsettling as these are associated with negative outcomes for the child. Physical aggression from the parent increases the risk of depression, anxiety, physical symptoms, medical diagnosis, and anger in the child (Springer, Sheridan, Kuo, & Carnes, 2007). The relationship between child maltreatment and the development of disorganized attachment relationships is highlighted in the meta-analysis of Cyr et al. (2010) suggesting that the continuous exposure of these children to parental abuse and neglect, is highly likely to have detrimental repercussions for the attachment security of the children from this sample. The cumulative risks for these children are increased by the socio-economic contexts in which the maltreatment takes place. Many of the children from the sample of mothers are exposed to poverty, high conflict environments, crime, mothers with low education, substance abuse by parents, and are raised in single parent households, which are all factors that are negatively associated with child psychological health (Appleyard, Egeland, van Dulmen, & Sroufe, 2005; Cyr, Euser, Bakermans-Kranenburg, & Van Ijzendoorn, 2010).

The consequences of these abnormal and hostile maternal behaviours were seen in the children reacting with fear and avoidance towards their mothers. In some cases where the mother is weak, children took on the caregiving role. This behaviour also resonates with disorganized patterns of attachment and may need to be investigated in future research (Moss, Cyr, & Dubois-Comtois, 2004; Solomon, George, & De Jong, 1995).

Social support plays an integral role in the well-being of the affected mother and her children and motivates medication adherence (Dyer, Stein, Rice, & Rotheram-Borus, 2012; Ncama et al., 2008). The value of social support was also reported by the mothers in the study and both groups (mothers with HIV with and without psychosis) recognized their family as the most important support figures. This is in contrast with findings from Kalichman, DiMarco, Austin, Luke, and Di Fronzo (2003) and Friedland, Renwick, and McColl (1996) that people with HIV seek and receive more support from friends than from family members. These studies were from Western populations with more individualistic cultures and therefore this difference can be expected in non-Western countries where collectivism is emphasised.

In both the qualitative and quantitative analyses, the mothers of the mothers with HIV associated psychosis were the most important support figures. Their support was highlighted in the role that they play as caregivers to their grandchildren. This caregiving role of grandmothers in the context of HIV has been recognized in the media, research, and government policies (Schatz & Ogunmefun, 2007). Chazan (2008) argues that a myth was created that this is a new trend caused by the HIV pandemic, but that grandmothers in most South African communities have always fulfilled the role of surrogate parents for their grandchildren. Grandmothers see this as a natural outcome when their children are not able to care for their grandchildren, whether it is due to death, illness, of working in different towns or cities (Schatz & Ogunmefun, 2007). Participants reported that most grandmothers took over the caregiving responsibilities entirely when the mother was physically or

psychiatrically ill and that some grandmothers still play an important parenting role. It gave the ill mother a sense of relief to know that there is someone to compensate for her mothering incapacity.

Being a support figure to a mother with HIV and a psychotic illness can be a burden on the family members. Awad and Voruganti (2008) reported that caregiver burden in caregivers of people with schizophrenia implied psychological, physical and economical strain and that caregivers often have to deal with embarrassment, guilt, shame and self-blame. Spouses of people with psychotic illnesses had lower psychological well-being and less social relationships, thus adding to their burden (Angermeyer, 2006). This could explain the poor spousal support reported by mothers with HIV associated psychosis. A diagnosis of psychosis predicted less spousal support and the mothers' narratives also confirmed that they experience their partners as unsupportive. The role of stigma and fear of being infected with HIV may add to the partners' reluctance to maintain spousal relationships.

Professionals were listed the least frequently as part of support networks (SIG). From the interviews it appeared as though professionals provided little else than medication. One possible reason for this could be that there is a lack of resources (Peterson & Lund, 2011) and specialized practitioners (Lund, Petersen, Kleintjes, & Bhana, 2012) to provide a more comprehensive service to those affected. Another factor that needs to be investigated is the effectiveness of communication between mental health care providers and –users. Bogart et al (2013) found that patient satisfaction and understanding can be improved by better communication between the parties involved. There is a need for cost-effective and culturally appropriate interventions at primary health care level (Peterson & Lund, 2011) with professional support extending to home visits in order to improve care (Wagner, Furin, Gripshover, Jeeah, & Jonsson, 2014).

It is clear that mothers with HIV associated psychosis experienced episodes of severe psychological and physical distress, influencing their well-being and functioning in such a manner that they were not able to care for themselves or their children. Additionally, in these times, their behaviour can become unpredictable and dangerous especially towards their vulnerable young children. In order to minimize the negative impact on these children, the affected mother needs a sensitive, stable and caring support network. The role of this support network will firstly be preventative and there must be an awareness of the possibility of mental health issues that can arise with HIV. Secondly, the support network must be sensitive to signs of ill health and respond empathically and timeously in order to decrease the child's exposure to possible harm in the affected parent's care. Lastly the support network needs to empower the mother to engage in healthy parent-child relationships, once she has regained a satisfactory level of health.

From this study it is evident that family members and specifically grandmothers form the largest part of the support network with spouses playing a lesser role. It is thus important for professional support figures to allocate more resources to the active support figures and to encourage spouses, especially fathers of the children to take on more responsibility. In order to effectively assist support figures more research is needed to examine the needs and experiences of support figures. In addition, the effects of the mother's illness on her children need to be investigated, especially attachment relationships as it may have long-term effects on the child's personality development. Once this has been assessed, more appropriate interventions can be implemented to ensure their well-being.

References

- Alvarez-Segura, M., Villero, S., Portugal, E., Mayoral, M., Montilla, P., & Fraguas, D. (2008). Psychosis induced by decreased CD4+ T cell and high viral load in human immunodeficiency virus infection: A case report. *Biological Psychiatry*, *64*(9), e3-4. doi: 10.1016/j.biopsych.2008.07.016
- Angermeyer, M. C. (2006). Quality of life of spouses of mentally ill people. *International Journal of Social Psychiatry*, *52*(3), 278-285. doi: 10.1177/0020764006067186
- Appleyard, K., Egeland, B., van Dulmen, M. H., & Sroufe, L. A. (2005). When more is not better: The role of cumulative risk in child behavior outcomes. *Journal of Child Psychology and Psychiatry*, *46*(3), 235-245. doi: 10.1111/j.1469-7610.2004.00351.x
- Association, A. P. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (Vol. 4). Washington DC: American Psychiatric Publishing, Inc.
- Boeije, H., Slagt, M., & van Wesel, F. (2013). The contribution of mixed methods research to the field of childhood trauma: A narrative review focused on data integration. *Journal of Mixed Methods Research*, *7*(4), 347-369. doi: 10.1177/1558689813482756
- Creswell, J. W., & Plano Clarke, V. L. (2007). *Designing and conducting mixed methods research*. LA: Lochshule.
- Cyr, C., Euser, E. M., Bakermans-Kranenburg, M. J., & Van Ijzendoorn, M. H. (2010). Attachment security and disorganization in maltreating and high-risk families: A series of meta-analyses. *Developmental Psychopathology*, *22*(1), 87-108. doi: 10.1017/S0954579409990289
- De Ronchi, D., Bellini, F., Cremante, G., Ujkaj, M., Tarricone, I., Selleri, R., . . . Scudellari, P. (2006). Psychopathology of first-episode psychosis in HIV-positive persons in comparison to first-episode schizophrenia: A neglected issue. *AIDS Care*, *18*(8), 872-878. doi: 10.1080/09540120500307842

- Dolder, C. R., Patterson, T. L., & Jeste, D. V. (2004). HIV, psychosis and aging: Past, present and future. *AIDS, 18*(Suppl1), S35-S42. doi: 10.1097/00002030-200401001-00006
- Dyer, T. P., Stein, J. A., Rice, E., & Rotheram-Borus, M. J. (2012). Predicting depression in mothers with and without HIV: the role of social support and family dynamics. *AIDS Behavior, 16*(8), 2198-2208. doi: 10.1007/s10461-012-0149-6
- Hosegood, V., Preston-Whyte, E., Busza, J., Moitse, S., & Timaeus, I. M. (2007). Revealing the full extent of households' experiences of HIV and AIDS in rural South Africa. *Social Sciences Medicine, 65*(6), 1249-1259. doi: 10.1016/j.socscimed.2007.05.002
- Jungbauer, J., Stelling, K., Kuhn, J., & Lenz, A. (2010). Wie erleben schizophran erkrankte Mütter und Väter ihre Elternschaft? Ergebnisse einer qualitativen Interviewstudie. *Psychiatrische Praxis, 37*(5), 233-239. doi: 10.1055/s-0029-1223535
- Konings, M., Bak, M., Hanssen, M., van Os, J., & Krabbendam, L. (2006). Validity and reliability of the CAPE: A self-report instrument for the measurement of psychotic experiences in the general population. *Acta Psychiatrica Scandinavica, 114*(1), 55-61. doi: 10.1111/j.1600-0447.2005.00741.x
- Lund, C., Petersen, I., Kleintjes, S., & Bhana, A. (2012). Mental Health Services in South Africa: Taking stock. *African Journal of Psychiatry, 15*(6). doi: 10.4314/ajpsy.v15i6.48
- McKee, L., Jones, D. J., Roland, E., Coffelt, N., Rakow, A., & Forehand, R. (2007). Maternal HIV/AIDS and depressive symptoms among inner-city African American youth: The role of maternal depressive symptoms, mother—child relationship quality, and child coping. *American Journal of Orthopsychiatry, 77*(2), 259-266. doi: 10.1037/0002-9432.77.2.259
- Moss, E., Cyr, C., & Dubois-Comtois, K. (2004). Attachment at early school age and developmental risk: Examining family contexts and behavior problems of controlling-

caregiving, controlling-punitive, and behaviorally disorganized children.

Developmental Psychology, 40(4), 519-532. doi: 10.1037/0012-1649.40.4.519

Ncama, B. P., McInerney, P. A., Bhengu, B. R., Corless, I. B., Wantland, D. J., Nicholas, P. K., . . . Davis, S. M. (2008). Social support and medication adherence in HIV disease in KwaZulu-Natal, South Africa. *International Journal of Nursing Studies*, 45(12), 1757-1763. doi: 10.1016/j.ijnurstu.2008.06.006

Papalia, D. E., & Feldman, R. D. (2012). *Experience Human Development* (12 ed. Vol. 1). New York: McGraw Hill.

Patton, M. (1990). *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage.

Peterson, I., & Lund, C. (2011). Mental health service delivery in South Africa from 2000 to 2010: One step forward, one step back. *South African Medical Journal*, 101(10), 751-757. doi: 10.7196/samj.4841.

Schatz, E., & Ogunmefun, C. (2007). Caring and contributing: The role of older women in rural South African multi-generational households in the HIV/AIDS era. *World Development*, 35(8), 1390-1403. doi: 10.1016/j.worlddev.2007.04.004

Shambley-Ebron, D. Z., & Boyle, J. S. (2006). 'Self-Care and mothering in African American women with HIV/AIDS': Commentary: Response by Shambley-Ebron and Boyle. *Western Journal of Nursing Research*, 28(1), 67-69. doi: 10.1177/0193945905282317

Solomon, S., George, C., & De Jong, A. (1995). Children classified as controlling at age six: Evidence of disorganized representational strategies and aggression at home and at school. *Development and Psychopathology*, 7(3), 447-463. doi: S0954579400006623

Spies, R., Sterkenburg, P. S., Schuengel, C., & van Rensburg, E. (2013). Linkages between HIV/AIDS, HIV/AIDS-psychoses and parenting: A systematic literature review. *Vulnerable Children and Youth Studies*, 9(2), 174-192. doi: 10.1080/17450128.2013.785641

- Springer, K. W., Sheridan, J., Kuo, D., & Carnes, M. (2007). Long-term physical and mental health consequences of childhood physical abuse: results from a large population-based sample of men and women. *Child Abuse Neglect, 31*(5), 517-530. doi: 10.1016/j.chiabu.2007.01.003
- Stefanis, N. C., Delespaul, P., Henquet, C., Bakoula, C., Stefanis, C. N., & Van Os, J. (2004). Early adolescent cannabis exposure and positive and negative dimensions of psychosis. *Addiction, 99*(10), 1333-1341. doi: 10.1111/j.1360-0443.2004.00806.x
- Tedlie Moskowitz, J., & Wrubel, J. (2005). Coping with HIV as a chronic illness: A longitudinal analysis of illness appraisals. *Psychology & Health, 20*(4), 509-531. doi: 10.1080/08870440412331337075
- Wagner, T., Furin, J., Gripshover, B., Jeenah, Y., & Jonsson, G. (2014). Loss to follow-up among a group of patients with HIV and severe mental illness in South Africa. *World Journal of AIDS, 04*(01), 74-80. doi: 10.4236/wja.2014.41009
- Wan, M. W., Moulton, S., & Abel, K. M. (2008). The service needs of mothers with schizophrenia: A qualitative study of perinatal psychiatric and antenatal workers. *General Hospital Psychiatry, 30*(2), 177-184. doi: 10.1016/j.genhosppsy.2007.12.001
- Wan, M. W., Penketh, V., Salmon, M. P., & Abel, K. M. (2008). Content and style of speech from mothers with schizophrenia towards their infants. *Psychiatry Research, 159*(1/2), 109-114. doi: 10.1016/j.psychres.2007.05.012
- Wan, M. W., Salmon, M. P., Riordan, D. M., Appleby, L., Webb, R., & Abel, K. M. (2007). What predicts poor mother-infant interaction in schizophrenia? *Psychological Medicine: A Journal of Research in Psychiatry and the Allied Sciences, 37*(4), 537-546. doi: 10.1017/s0033291706009172

Wan, M. W., Warren, K., Salmon, M. P., & Abel, K. M. (2008). Patterns of maternal responding in postpartum mothers with schizophrenia. *Infant Behavior & Development, 31*(3), 532-538. doi: 10.1016/j.infbeh.2008.04.003

Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociol Health Illness, 29*(4), 610-626. doi: 10.1111/j.1467-9566.2007.01008.x