

Chapter 5

Exploring the role, needs and challenges of relatives of mothers with HIV or HIV and psychosis: A qualitative study

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Abstract

This study explored types and nature of supports by relatives of mothers living with HIV and psychosis in comparison to mothers with HIV only. Interview data on their experiences of their roles, needs, and challenges were collected from 33 relatives of mothers with HIV and psychosis ($n = 12$, females = 10, Black-African = 12, age ranges 21 to 62) and those with HIV only ($n = 21$, females = 16, Black-African = 21, age ranges 18 to 63). The data were thematically analysed utilizing Atlas.ti. The results showed that relatives in both groups provided a variety of supporting roles. Important challenges were experiencing the negative consequences of especially HIV in combination with psychosis in their lives and dealing with the caregiving responsibilities without having enough information. Important strengths included utilizing support networks and remaining hopeful. Support needs for carers of mothers living with HIV related psychosis or HIV only can be enhanced with increasing social and material resources at the community level. Supporting needs can be addressed by empowering communities through psycho-education.

HIV/Aids is highly prevalent in South African women of child bearing age, and places considerable demands on relatives in a country where access to professional support is limited. Little is known about the additional demands that result from comorbid syndromes, of which psychosis is an important one. Approximately 6.4 million people lived with HIV in South Africa in 2012, and women at the ages of 20 to 34 ran the greatest risk of contracting the disease (Shisana et al., 2014). Many of these women have children, adding to their subjective burden living with HIV. Later stages of HIV can induce HIV-associated psychosis as a psychiatric response to the disease in vulnerable individuals or as a consequence of damage to the brain (Chandra, Desai & Ranjan, 2005). Comorbid conditions that accompany HIV and AIDS such as psychosis add to carer support demands. Psychosis related symptoms in the mothers may potentially disrupt the quality of relationships with significant others, including children (Spies, Sterkenburg, Schuengel & Van Rensburg, 2013). Social support from relatives is important to people living with chronic illness such as HIV (Sorsdahl & Stein, 2010). However, in cases where mothers have a condition like psychosis, giving support may incur specific difficulties that are currently not well known.

Extant studies reviewed by Antle, Wells, Goldie, DeMatteo, and King (2001) have revealed that one of the reasons why providing care to relatives with HIV can be so stressful is because HIV often means that there is great uncertainty about health and the future. A qualitative study by Stajduhar and Davies (1997) summed up the care giving experience as “an intense, emotional, and powerful experience filled with pride and enrichment, and conversely, with anger and disillusionment” (p. 1). At the same time, timely and appropriate supports by family or relatives would enhance overall health and wellbeing of both the people living with HIV (and psychosis) and networked others (Spies, Sterkenburg, Van Rensburg & Schuengel, 2015). The 0.2 to 15% of HIV positive individuals who develop psychosis (Alvarez-Segura, Villero, Portugal, Mayoal, Montilla, & Fraguas, 2008; Dolder, Patterson,

& Jeste, 2004) may present with unique challenges to care. Saunders (2003) reported that relatives caring for individuals with severe mental illness experienced heightened stress, moderately high levels of burden, and seldom felt that their own support needs were being met. Little research has focused on carer relative support for mothers with HIV and comorbid disorders in high risk settings like South Africa. This study investigated the types and nature of supports provided to mothers

In order to increase insight into the diversity of roles, needs and challenges that relatives experience and to better understand the unique challenges associated with psychosis as a condition comorbid to HIV, this study aims to explore the perspectives of relatives of mothers with HIV and HIV in combination with psychosis. In particular, individual as well as group differences were qualitatively explored among the relatives of affected mothers. The specific research question was: "What are the roles, needs and challenges of relatives of mothers with HIV or HIV and psychosis?"

Methods

Participants and Procedure

This study is part of a larger research project on parenting in the context of HIV/Aids and psychosis. For the larger research project mothers were recruited from various outpatient facilities of psychiatric hospitals as well as HIV clinics in general hospitals in the North-West-, Gauteng- and Kwa-Zulu Natal provinces of South Africa, based on their availability. Two hundred and twenty seven mothers were invited by health care workers from the clinics and hospitals to participate in the larger study and 85 mothers gave informed consent for participation (females = 79%; Black-African = 100%). Participants were not asked to provide reasons for not participating. Mothers' diagnoses of HIV were known to them as they were tested at the respective medical facilities and they did receive pre- and post-test counselling.

Mothers with a diagnosis of HIV and psychosis were diagnosed by a multidisciplinary team consisting of a minimum of a psychiatrist, psychologist, social worker and nursing staff based on observed criteria of the DSM-IV-TR (APA, 2000). Duration of illness and the cause of the psychotic disorder were unknown to the researchers.

Mothers with HIV and HIV related psychosis who participated in the larger research project were asked to invite a relative whom they regarded as an important support figure to participate in this study. Of the possible 85 relatives, 33 participated. Reasons for not attending included lack of time due to work or other responsibilities. The identified relatives who acted as support figures for these mothers were 26 women and 7 men. The average age of relatives was 37.2 (SD =14) (see Table 1). Before each interview, written informed consent was obtained. Interviews of participants were conducted in a designated office at a North West University Campus. All other interviews were conducted at the respective hospitals. Transport was provided for all participants. No incentives were provided for participating relatives, apart from refreshments.

To respect confidentiality of affected mothers' HIV-statuses and psychiatric diagnoses, each relative was asked beforehand if they knew why they were invited to participate in the research. If the relative was not aware of the affected mother's HIV-status the interview was either stopped or conducted in a way in which diagnoses were not revealed. This only happened during two of the interviews. In the first case a review of the content indicated that the interview was stopped and data from the interview were excluded from the analyses. In the second case the relative knew that the mother was ill and then interviewers spoke about "the illness" without referring to HIV/Aids. In total, 33 semi-structured interviews were conducted by the researcher with the relatives; 21 relatives of mothers

infected with HIV alone (females = 16) and 12 relatives of mothers infected with HIV and psychosis (females = 10).

Table 1.

Participant Age, Affiliation to Primary Participant and Diagnosis

No.	Age	Relative	Diagnosis	Town	Language
1.	60	Mother	HIV and psychosis	Potchefstroom	Tswana
2.	22	Niece	HIV and psychosis	Stilfontein	Tswana
3.	53	Mother	HIV and psychosis	Ventersdorp	Tswana
4.	44	Sister	HIV and psychosis	Orkney	Tswana
5.	50	Mother	HIV and psychosis	Stilfontein	Tswana
6.	48	Sister	HIV and psychosis	Potchefstroom	Tswana
7.	45	Sister	HIV and psychosis	Potchefstroom	Tswana
8.	62	Cousin	HIV and psychosis	Potchefstroom	Tswana
9.	26	Brother	HIV and psychosis	Johannesburg	Zulu
10.	32	Sister	HIV and psychosis	Johannesburg	Zulu
11.	21	Daughter	HIV and psychosis	Potchefstroom	Xhosa
12.	36	Friend	HIV and psychosis	Stilfontein	Tswana
13.	21	Sister	HIV	Potchefstroom	Tswana
14.	31	Friend	HIV	Potchefstroom	Tswana
15.	29	Boyfriend	HIV	Potchefstroom	Sotho
16.	55	Mother	HIV	Potchefstroom	Tswana
17.	47	Husband	HIV	Potchefstroom	Tswana
18.	35	Aunt	HIV	Potchefstroom	Tswana
19.	22	Sister	HIV	Potchefstroom	Tswana
20.	63	Mother	HIV	Potchefstroom	Tswana
21.	54	Mother	HIV	Potchefstroom	Tswana
22.	35	Husband	HIV	Potchefstroom	Afrikaans
23.	29	Sister	HIV	Potchefstroom	Sotho
24.	37	Sister	HIV	Potchefstroom	Sotho
25.	26	Sister	HIV	Potchefstroom	Tswana
26.	19	Daughter	HIV	Potchefstroom	Tswana
27.	18	Niece	HIV	Potchefstroom	Tswana
28.	43	Sister	HIV	Potchefstroom	Tswana
29.	19	Sister	HIV	Potchefstroom	Tswana
30.	20	Sister	HIV	Potchefstroom	Tswana
31.	55	Aunt	HIV	Potchefstroom	Tswana
32.	32	Boyfriend	HIV	Potchefstroom	Tswana
33.	37	Boyfriend	HIV	Potchefstroom	Tswana

Data Collection

A qualitative research design was chosen as it was the most appropriate method of gaining in-depth narratives of the participants' experiences. Semi-structured interviews were utilized to collect data from carer relatives on their experience providing support to mothers with HIV or HIV with psychosis who were relatives. Interview questions centered on the role and the needs of relatives. Example questions were, "What was your role/involvement with regards to her (affected mother) child when she was ill?" or "What is your current role with regards to support?" and "What made it easier or difficult to fulfil this role?" The interviews were all conducted by the first author who is English speaking. Participants were however encouraged to communicate in their mother tongue and then interpreters participated. Four interpreters who were Tswana, Sotho, and Zulu speaking were trained by the first author to facilitate (translate) the interviews. Four separate translators, who were Setswana speaking post-graduate students from the African languages department of the North West University who were not part of the data collection phase transcribed the audio-recorded interviews verbatim to English; specifically the dialogue between the participant and the translator. This was done to ensure that none of the information in the interviews was omitted during translation.

Data Analysis

Interviews were analysed in the software programme Atlas.ti 7. The interviews were first analysed blind to status as HIV only or HIV and psychosis. After final analysis, group membership was identified to examine possible differences between groups. The interviews were analysed independently by the first and second authors using Atlas.ti 7 software and examined according to thematic analysis, a flexible and theory-free approach to data analysis (Braun & Clarke, 2006). This approach consisted of six different phases as described by

Braun and Clarke (2006). In the first phase, the coders familiarized themselves with the data by repeated reading. In the second phase, initial codes were generated. Direct quotes were grouped under one particular code to provide examples for the code. In the third phase, themes were constructed by grouping codes according to similarity. In the fourth phase, themes were reviewed with the purpose of making sure that the codes optimally fitted into the themes they were assigned to. In the fifth phase, themes were defined and labelled. In the sixth phase, a report of the themes was produced. In this report, themes that related to each other were grouped into dominant frameworks.

The number of times that participants spoke about each of the themes as divided by the number of interviews was recorded to provide an index of its importance. For example, when a theme was coded 44 times, it was divided by 33 interviews, $44/33 = 1.33$. The resulting number was reported in parentheses at the end of each theme. Because there was an unequal number of interviews in the two groups, dividing the number of frequencies by the actual number of interviews for both groups was crucial to provide an accurate account of occurrence of particular themes among the two groups. If for example a theme was coded 25 times for relatives in the HIV only group, then the frequency was divided by 21, $25/21 = 1.19$. In addition, the identification number of the respondents was added after each quotation to indicate the reference to the data as well as the participant's gender and age, such as "M001, female, 21 years."

Credibility

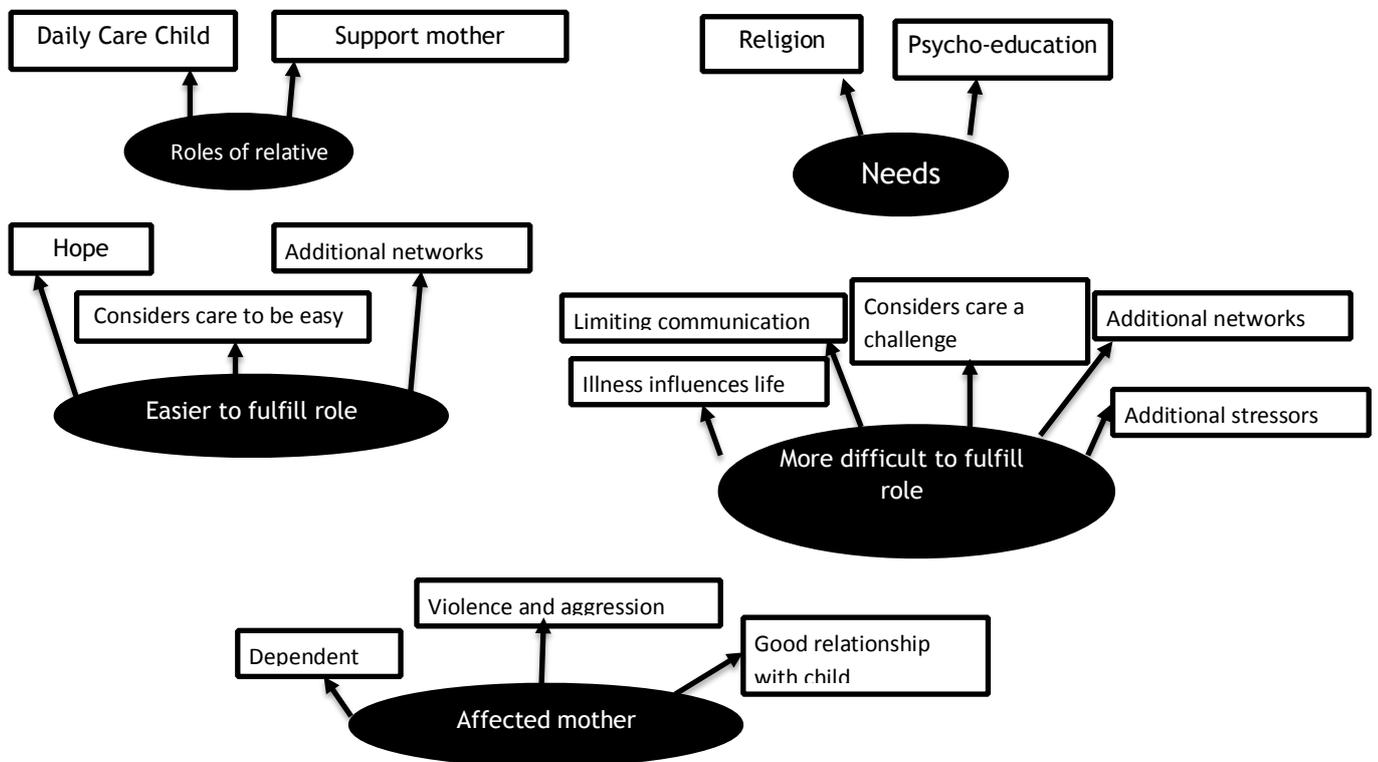
To ensure credibility of the data analysis the first and second authors conducted the entire process of data analysis independently, following the same procedure as described above. They then conducted a consensus review at two separate occasions, firstly after the themes were identified and then secondly when the dominant frameworks were established.

Minor differences in the results were discussed and changes to the framework were agreed upon by both authors. Lastly this process of review was discussed with the third author. Ethical approval for the project was received from the North West University Ethics Committee with ethics number NWU-00046-12-A1.

Results

Five dominant frameworks were identified in which themes were grouped (see Figure 1). The first framework encompassed the support roles of relatives; the second framework encompassed relatives' own needs in order to provide support; the third and fourth frameworks described what made it easy and difficult to support affected mothers. The fifth framework dealt with the ways in which mothers themselves facilitated or complicated the provision of support.

Figure 1. Final thematic map, showing final 5 main themes



Role of Relatives

An important supporting role was child rearing or caring for the affected mother's children. According to the interviews, many of the relatives (97%) provided daily care to the children ($37/33 = 1.12$), with 48% of the relatives reporting caring for the children when the affected mother was absent due to illness or other reasons (0.55). As a result, relatives became a substantial part of the child rearing process. One relative reported, "I became the primary caregiver; the children were in my care when my daughter was in the hospital (M006, female, 53 years)" or "the time when she (affected mother) was sick, I used to go and stay with her. I would take care of her and the child (M022, female, 35 years)" or "her boyfriend took her to hospital and I took her kids to my house (M011, female, 36 years)". About 21% of relatives identified the quality of the relationship of the affected mother with her child (0.24) as a facilitator of support. For example, one relative reported, "She (affected mother) used to leave and not come home to visit for a period of 12 months without seeing her kids, she left the other one in (town where she stayed) and we had to go and get him from the social workers. It was difficult. Now she's more of a mother to her kids and they have a bond (M005, female, 22 years)".

In addition to providing daily care, relatives also reported to provide financial (0.15 or 15%), emotional (0.76 or 72%), practical (0.45 or 30%) and overall support (0.58 or 57%) for the mothers. With regards to financial support, a relative said, "I help with money for food and electricity (M040, male, 62 years)". Emotional support was reported to be given by relatives who also suffered from HIV. They seemed to understand what the affected mother was going through as one relative noted, "because I already know the stage, I will stay with her and comfort her (M022, female, 35 years)" or "after she told me that, I started comforting her (M022, female, 35 years)" or "we talk to share advices (M005, female, 22 years)". In

terms of practical support, many relatives said that they help with daily chores. For instance, one relative said, "I do her laundry, clean the house, and cook (M008, female, 44 years)". A majority (95%) of the carer relatives of the HIV only group reported to provide daily care (1.38) than relatives of the HIV and psychosis group (0.66). Furthermore, relatives in the HIV only group also reported to provide more support (2.1) than relatives in the HIV and psychosis group (1.66).

Needs of Relatives

Participants identified religion and psycho-education as important to their caring of mothers living with HIV. This is illustrated by one relative who noted, "the church gave us a lot of comfort (M003, female, 60 years)" or by another who said, "we knew that it was God's will and we thought that if this was what he chose for her, then he will show us a way out of it (M011, female, 36 years)".

Psycho-education about HIV, provided by health care workers, was reported important to carer roles by the participants. Relatives of the HIV and psychosis group more often reported not receiving psycho-education (1.67 or 83%) than reporting that they received it (0.5 or 25%). Consequently, psycho-education was identified as a possible unmet need of relatives. Relatives of mothers with HIV only were less likely to report to be religious or use religion as a way of support (0.09 or 9 %) as compared to relatives of the HIV and psychosis group (0.75 or 70%).

Aspects making it easier to fulfil a helpful role

The participants reported hope for the future as an important resource for caring for relative mothers with HIV (0.51). Participants reported social support networks consisting of other family members or friends (0.19) and the perception of caring as easy or

not (0.7) important to their carer roles. Caring was considered easier for relatives when caring was seen as 'normal' or a given, when the affected mother cooperated in the helping process. or when relatives considered having a family bond between them and the affected mother and child. Relatives of mothers with HIV only often perceived HIV as an ordinary disease which needed typical support resources as for others without HIV. Other relatives simply concluded that helping is something normal. For example, one relative noted, "when someone is in need, one should not turn your back on them...it is like helping your neighbour in hard times. Maybe they will help you when you experience problems too (M040, male, 62 years)". Another relative noted: "it's not hard for me because she is my sister's child (M022, female, 35 years)" or "it was easy because they are my grandchildren (M003, female, 60 years)". Relatives of the HIV only group less frequently reported to be influenced by the illness/situation (0.34) compared to reports from relatives of the HIV and psychosis group (2.83).

Surprisingly, a greater proportion of relatives of mothers from the HIV only group (23%) reported less often being hopeful (0.28) compared to the relatives in the HIV and psychosis group (0.92 or 83%). Also surprisingly, relatives of the HIV only group reported less often to have additional networks available (0.09) as compared to the relatives of the HIV and psychosis group (0.33).

Aspects that make it more difficult to fulfil a helping role

From the interviews there were a number of aspects identified that made the helping role more difficult for the relatives. The first pertained to the impact that the illness or the burden of caring has on the relatives' lives. It became evident that the circumstances of the affected mothers, infected with HIV alone or HIV and psychosis, influenced relatives' lives in several ways. Many of the relatives (97%) reported that they were influenced by the situation

(1.25), for example by having trouble sleeping and possibly having their sleeping pattern interrupted (0.22). For instance, one of the relatives reported, "I couldn't sleep thinking about her (M003, female 60 years)" and another one said, "I have very vague dreams and I can't remember what they are about (M006, female, 53 years)". For other relatives, the stress impacted them physically such as through high blood pressure (0.03), diabetes (0.03) or heart problems (0.03). And for yet others the stress had an economic impact, as they were forced to leave their job (0.22). Overall caring for relatives appeared to imply a lot of stress. As a result, many of the relatives also reported to have reacted emotionally towards the situation (1.51). Some of the relatives reported to be hurt (0.08), sad (0.06), and that the situation they were in was painful (0.03), heavy (0.03), and bad (0.03) for them.

Support was reported to be more difficult with limited communication (0.25), additional stressors (1.97), viewing one's own help as a challenge (0.73), and hopelessness about the future and living with HIV (1.18). For instance, limited communication included perceptions of little dialogue about HIV: "We never talk about HIV (M024, female, 22 years)" or another relative who said, "She's not usually talking to me about her pains (M032, female, 19 years)". It could also be that the affected mother simply did not initiate conversations herself but only talked when forced such as this relative who shared, "she ended up talking to me about it because I confronted her (M032, female, 19 years)".

Social stressors on the patient also added to the carers' subjective burden. Some of the additional stressors included that the mother lost her parents (0.03), boyfriend (0.06), had her child infected with HIV (0.09), or had financial difficulties (0.03).

Characteristics of the affected mother influencing support

The affected mother herself was perceived as an important factor influencing the level of difficulty for relatives to serve as a support figure. Relatives noted that the dependency of the affected mother on the relative (0.19), such as not being able to do any household chores by herself, and her violent and aggressive behaviour (0.55) hampered the provision of support. To exemplify the dependency of the affected mother, one relative said, “she was just a useless thing; she couldn’t do anything for herself (M003, female, 60 years)” and another relative noted, “right now she can’t do anything. She can’t even wash herself (M027, female, 54 years)”. While the dependency of the affected mother was not as pervasive throughout all interviews, the violent and aggressive aspects of the affected mother appeared frequently, suggesting to have a significant influence on the relatives. One relative reported the affected mother to be, “violent and stubborn (M009, female, 50 years)” or “aggressive and fighting and irritated (M020, female, 45 years)” and another relative noticed that the affected mother “was hitting her child and she was not safe (M005, female, 22 years)”.

Besides making caring more difficult, there were also other aspects of the affected mothers that could make caring possibly easier for the relatives. Relatives of the HIV only group less frequently reported the affected mothers to be dependent (0.04) than relatives of the HIV and psychosis group (0.42). Additionally, relatives of the HIV only group (0.28) reported more often that the affected mothers had a good relationship with their child than relatives of the HIV and psychosis group (0.17). This frequency was not unanticipated because the added psychosis was expected to make it more difficult to maintain a good relationship for the affected mother and her child.

Discussion

Comorbid HIV with psychosis placed high demands of care on relatives. Participants from this group voiced the need for extra resources in the form of religion and psycho-education. Social support was important to carer roles with HIV or HIV and psychosis. Spies and his colleagues (2015) found that mothers with HIV had an equal number of support networks compared to mothers with HIV and psychosis and therefore it appears as though the assumed lesser need for support only resonates with the support figures and not with the mothers with HIV themselves. It is evident that the support networks of both groups experienced needs and challenges in fulfilling their role, but that the addition of psychotic symptoms placed more strain on the support networks of mothers with HIV and psychosis, as was also found in a study of mothers with schizophrenia (Bademli & Cetinkaya Duman, 2011). This is echoed in support figures' needs for additional support from other community members such as friends and family, but also in their reaching out to formal helpers such as religious institutions and hospitals (Ramirez-Avila et al., 2014).

It is important to note that this group of support figures reported that the demands exceeded their capacity to support. This can have detrimental consequences for their own health and well-being (Awad & Voruganti, 2008) as well as their abilities to adequately fulfil their supporting roles. The dependency of mothers from both groups on their support networks for financial, emotional, practical and overall support highlights the importance of these networks. This dependency is especially true for mothers with HIV and psychosis and is also emphasized in the study by Spies and his colleagues (2015) where mothers with HIV and psychosis reported in some cases that their survival depended on their support relationships.

From the interviews it can be hypothesized that HIV is perceived as a common illness, in contrast with psychosis. This is in line with findings by Ramirez-Avila and colleagues (2014) who reported that South Africans' knowledge about HIV and willingness to be tested has increased over the past four years. Sorsdahl and Stein (2010) also reported that community members still lack knowledge about the psychobiological aetiologies of psychotic disorders such as schizophrenia. The support networks' lack of knowledge of severe mental illnesses creates a need for better understanding through psycho-education.

The combination of poor understanding of the illness together with the burden of caring for a mother with HIV and psychosis may have led to more negative perceptions in this group compared to the HIV only group. Factors that alleviate some of the burden were identified such as cooperation from the mother, the bond between the family and the mother and child, perceptions of support as normal, hope, and additional support networks. Previous research has shown that good family bonds may moderate burden associated with caregiving (Johnson, 2000).

The fact that the HIV only group less often reported having additional support networks may indicate a lesser need for additional support, as they also more frequently reported caring to be easy. Yet this group of relatives of mothers with HIV only reported more additional stressors such as unemployment, death of parents and substance abuse than the HIV and psychosis group. This was also found to be evident in a study by Stajduhar and Davies (1997). It may be possible that the severity of the impact of the psychotic symptoms may overshadow other stressors, but this is a hypothesis that needs to be tested in future research. This can be viewed in the light of the fact that both groups reported similar socio-economic contexts on the demographic particulars questionnaire completed by the affected mothers at the onset of the interviews. The affected mothers' own behaviour influenced

perceived burden of care, for instance, poor communication, especially in the HIV only group can make it difficult for support figures to fulfil their role (Saunders, 2003). However this group is also less dependent on their support networks, which lessens the demands on their relatives.

The mothers of the HIV and psychosis group have more functional impairments, making them more dependent. Furthermore, the HIV and psychosis group also experience more violence and aggression from the mothers. Exposure to physical aggression has been associated with increased levels of posttraumatic stress disorder (PTSD) in psychiatric nursing staff and relatives who care for people with psychosis (Loughland et al., 2009). Additionally, the mothers with HIV and psychosis tended to have poorer relationships with their children compared to the mothers from the HIV only group. This poor relationship between mothers and their children, especially in the HIV and psychosis group, appeared to have a negative impact on their supporting relationships with relatives.

Clinical Implications

Relatives of affected mothers with HIV and psychosis need greater assistance from professionals to better cope with the particular type of stress associated with psychosis. More assistance from professionals for affected mothers will also likely alleviate some of the pressure that is placed on the family members. Professionals can play a mediating role, helping to improve communication between affected mothers and supporting family members so that needs and challenges can be addressed directly. Professionals can help family to understand the illness and make them aware of the possible behavior to look out for to ensure help is provided to the mother before symptoms escalate. Furthermore the important role that relatives play in the rearing of affected mothers' children is recognized, both in providing in

their physical needs as well as creating emotional safety in times of turbulence. This can have enduring benefits for the healthy development of a group of very vulnerable children.

Limitations of the study.

It is necessary to note that this study is exploratory and based on a qualitative approach, which is why the reported frequencies should not be generalized. Although frequencies provide a useful overview suggesting how common a particular theme is within and across all interviews, they do not say much about the significance of a theme. In order to examine the importance of that behaviour and how much it actually influences the care relatives are capable of providing, quantitative research is needed.

Conclusion

From the interviews it is inferred that both groups of support figures (HIV only and HIV and psychosis) played an important role, firstly towards the mothers and secondly towards the mothers' children. For the mothers they provided emotional, financial, practical, and overall support and for the children they played an important part in the rearing. As expected, the HIV and psychosis group reported a higher burden than the HIV only group. These additional burdens such as the mother's dependence due to physical debilitation and higher incidences of violent and aggressive behaviour impeded the support network's capacity to fulfil their roles as support figures for the mothers with HIV and psychosis. Thus, comorbid psychosis warrants additional attention towards the support network.

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