# "MY MOTHER HAS AIDS": STORIES OF ADOLESCENTS LIVING IN KHAYELITSHA, SOUTH AFRICA

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#### Abstract

#### Background

HIV/AIDS is associated with death and for children death becomes a potential reality when they live in a household where a parent has HIV/AIDS. The aim of this paper is to (a) explore the perceptions of and experiences of adolescents living in households where the mother had HIV/AIDS, and (b) to describe the coping mechanisms used by adolescents in these households.

#### Methods:

A narrative approach was used to explore participants' story telling. Detailed interviews were conducted with 6 purposively selected isiXhosa-speaking adolescents between the ages of 12 and 15 in Khayelitsha. Narrative analysis was used to analyse the data.

#### **Results:**

The stories reveal experiences of being told about the news of the mothers' illness, how they eventually coped, how they accepted the situation and the experiences of other people knowing that their mothers had HIV/AIDS. Overall, the stories reflect that the participants were coping with the mother being HIV/AIDS-positive and maintained hope for their future.

#### Conclusions:

Stories reflected the emotionally challenging situations adolescents face. In order for adolescents to cope within these challenging situations the environment needs to be supportive. This environment includes parents, family and friends. Government should implement relevant programmes and support structures, which could also on combating stigma and discrimination.

**Key words:** Adolescence, coping mechanisms, HIV/AIDS, mother-adolescent relationships, narrative research, psychosocial well-being, South Africa

### Introduction

The prevalence of HIV/AIDS in South Africa has steadily increased over the past two decades, with 5.7 million AIDS sufferers in South Africa during 2009 (UNAIDS, 2009). Additionally, it is estimated that 413 000 South Africans contracted HIV during 2009 alone (Statistics South Africa, 2009). The prevalence of HIV is higher amongst females than males in South Africa (Roman, 2006). Often, HIV/AIDS is associated with death. Children living in households where a parent is ill with HIV/AIDS, have to witness the process of the illness (Simbayi et al., 2006). In South Africa, children affected by HIV/AIDS through parental illness, suffer in terms of material loss, stigma and discrimination, loss of parental love and support, malnutrition, household economic deterioration, loss of educational opportunities, and having to take over adults' roles and responsibilities (Davids et al., 2006; Mbambo, 2005; Ranchod, 2005; Richter, 2004 ). Furthermore, emotional distress and depression are often displayed when exposed to a parent suffering from HIV/AIDS-related illnesses (Bauman et al., 2006; Gunther, Grandles, Williams & Swain, 1998). For adolescents, this exposure may be much more difficult to manage.

Adolescents are particularly vulnerable since adolescence is a transitional period of human development (Black, 2009). During this period of development, adolescents are in the difficult process of forming an identity, while at the same time there is a disruption of roles since the family has to restructure in order to accommodate the effects of the mother's illness (Bauman et al., 2006; Tompkins & Wyatt, 2008). Often adolescents living in households with mothers who have HIV/AIDS compromise their independence as they have to be more supportive to their mothers (Bauman et al., 2006; Black, 2009; Lee, Lester & Rotheram-Borus, 2002). Loss of independence may result in adolescents being more vulnerable, often resulting in disempowerment, depression, low self-esteem and even suicidal thoughts (Jonson, 2009). Additionally, adolescents are at risk of developing psychosocial problems such as poor academic performance, anxiety, fear, behavioural problems and loneliness (Linsk & Mason, 2004; Tompkins & Wyatt, 2008).

Being affected by HIV/AIDS, adolescents are exposed to stressors from society. Stigmatisation and discrimination are often the main stressors to which adolescents are exposed (Deacon & Stephney, 2007). Often adolescents have been perceived as evil and immoral (Campell, Foulis, Maimane & Sibiya, 2005; Deacon & Stephney, 2007; Lyon & D'Angelo, 2006). These perceptions are based upon socially constructed ideas and beliefs that people who have HIV/AIDS are sinners, sexually immoral and promiscuous (Francis & Francis, 2006; Soskolne, 2003). Subsequently adolescents who experience stigmatisation may acquire self-stigmatisation. According to Corrigan, Larson and Rusch (2009: p. 75), self-stigmatisation occurs in three steps: "awareness of the stereotype, agreement with it, and applying it to one's self." Selfstigmatisation creates a high level of vulnerability, as the affected individuals are at risk of continuing risky behaviours due to self-pitying and a lack of selfvalue. Disregarded and belittling treatment of adolescents affected by HIV/AIDS leaves them with limited coping mechanisms such as hope, or sometimes no coping at all because of a lack of

social and family support (Molassiotis et al., 2002; Nashandi, 2002).

Adolescents are often plagued by thoughts concerning the future, such as who would take care of them should the parent die (Richter, Manegold & Pather, 2004) and how they would cope without parental support and love (Strode & Barret-Grant, 2001). Lazarus and Folkman (1980) have categorised coping mechanisms as problemfocused and emotion-focused. Problem-focused coping occurs when a person identifies factors that caused or do cause the problem, and then devises means and ways to deal with that in an effective manner (Rose & Clark Alexander, 1999). This type of coping is also known as confrontative and goaldirected. According to Melnick, (2001) problemfocused behaviour is directed at defining the problem, gathering alternative solutions, comparing the costs and benefits, and then deciding and acting on a suitable solution. Rose and Clark Alexander (1999) state that emotion-focused coping occurs when a person chooses to avoid the problem, and carries on as if what has happened does not matter, and that there is no need to address the consequences thereof. However, in other cases, the person may be avoiding the problem in order to maintain hope and optimism. Emotion-focused coping is also known as passive and emotive coping, and it is usually exercised when a person believes that she or he is unable to change the situation (Rose and Clark Alexander, 1999).

Studies examining adolescents' coping mechanisms have focused on the psychosocial challenges during adolescence, as well as living in households where a parent or both parents have HIV/AIDS (Gunther et al., 1998; Nkosi, 2006; Lyon & D'Angelo, 2006; Shebi, 2006; van Niekerk, 2003). Studies which examined the emotional well-being of these adolescents have reported that the majority were found to be emotionally distressed, displayed behavioural problems, had low self-esteem, and suffered from depression (Black, 2009; Lee, Lester & Rotheram-Borus, 2002; Richter, 2004). How adolescents and parents cope with the effects of HIV/AIDS plays an important role in their future psychological well-being. The aim of the present study was therefore to (a) explore the perceptions of and experiences of adolescents living in households where the mother had HIV/AIDS, and (b) to describe the coping mechanisms used by adolescents in these households.

## Methods

This study used a narrative approach in order to explore the stories of adolescents living in households with mothers suffering from HIV/AIDS. The narrative approach is a method which provides a voice to the marginalised, expressing language, meaning and interpretation, in order for persons to share their self-experience (Chadwick, 2001; Soskolne 2003: 4). For this particular study, the focus is on the stories which adolescents wished to share regarding their experiences of living in households where the mother was HIV/AIDSpositive. By telling their stories, these adolescents were able to comprehend their past experiences as well as their future, thereby linking together sequences of events into a meaningful whole constructing their own reality (Crossley, 2000a, 2000b; Davies, 1997; Ezzy, 2000; Hayden, 1997, Polkinghorne, 1988; Sabrin, 1986).

A purposively selected sample of adolescents, whose mothers were attending a support group at a Non-Governmental Organisation (NGO) for people living with HIV/AIDS, was selected. This NGO offered support groups through integrated programmes of prevention, care and support for both children and adults infected and affected by HIV/AIDS. The sample consisted of 6 participants (2 males and 4 females) aged 12 to 15 years, who were isiXhosa-speaking. The participants were families living in Khayelitsha. Permission to conduct the study was granted by the University of the Western Cape and the manager of the NGO. Participants were provided with information regarding the study, their rights to participate and withdraw, confidentially and anonymity in participating in the study. Participants thus consented to voluntary participation. Since the participants were under 18 years of age, parents consented to the participation of their children in the study.

Semi-structured individual face-to-face interviews were conducted in isiXhosa, which was the participants' mother-tongue in a secluded room at the participated NGO's offices. Broad topics were covered including children's life experiences before and after the mother became ill with AIDS (e.g. daily life at home and at school, relationships with peers, mother-adolescent relationships, experiences within the community and their plans for the future). Participants provided permission to audio record the

#### interviews.

Crossely's (2000a) 6 steps for analysing the data were used to analyse the data. Step 1 included reading and familiarisation with the data. During this step, the researcher was able to give each narrative voice an appropriate intonation and expression, formulating a mental picture of the story's action (Manfred, 2005). The researcher thoroughly engaged with the story, and became familiar with different textual voices in order to establish who was telling the story, what the message was, and how it was conveyed. The next step entailed identifying *important concepts.* During this step three principal elements were identified, namely narrative tone, imagery and themes. In step 3, narrative tone was identified, and in step 4, imagery and themes were identified and the case stories were collectively analysed for coherency, patterns, emotional tone and narrative style, as storytellers cognitively and emotionally processed their experiences.

## Findings

## Characteristics and overview of the participants

Participant 1 was a 13-year-old girl, the youngest of three children. She was in Grade 6 at the local primary school. Not much was mentioned about the father. Her mother worked as a labourer and was the breadwinner of the family. The participant was hurt by her mother's HIV/AIDS status. While she was still trying to find her way to cope with the situation, her mother started drinking. At the time of the interviews, the participant felt emotionally hurt, but still hoped that her mother's drinking situation would end.

Participant 2 was a 15-year-old girl in Grade 12 at the local high school and the youngest of two children. The participant lived in a household with both parents. Both the parents were unemployed at the time of the interview. The participant was hurt by her mother's HIV/AIDS status, but reported during the interview session that she was coping with the situation. She felt hurt by other family members' negative reaction towards her mother's situation.

Participant 3 was a 14-year-old girl in Grade 5 at the local primary school and the eldest of four children. Her parents had been divorced three years before the interview. Her mother worked as a labourer and was the breadwinner. The participant was coping well with her mother's HIV/AIDS status. She reported

that she was coping because of her mother's ability to cope with the situation but felt shattered by other family members' negative reaction to her mother's situation.

Participant 4 was a 15-year-old boy, the second eldest of 6 children, completing Grade 9 at the local high school. Not much was said about the father. His mother worked as a labourer and was a breadwinner. The participant was hurt by his mother's HIV/AIDS status, and did not seem to be coping with the situation. He felt hurt by his mother's inability to provide for the family because of her HIV/AIDS status. He felt that he and his siblings were suffering the consequences.

Participant 5 was a 14-year-old girl completing Grade 9 at the local high school and the youngest of four children. Not much was said with regard to her father. Her mother worked as a labourer and was the breadwinner. The participant was hurt by her mother's HIV/AIDS' status and did not seem to be coping so well with the situation at the time of the interview.

Participant 6 was a 14 year-old boy, completing Grade 8 at the local high school, the eldest of three children and lived in a household with his mother and stepfather. His mother was HIV/AIDS-positive. Both parents were labourers doing everyday jobs. He reported that he was coping well with his mother's situation. He explained that his coping abilities were due to his knowledge that AIDS does not kill people who manage themselves well by treating it and visiting the clinic.

On being told that their mothers were HIV-positive, participants seemed to move between the self and the outer world. They told their stories according to their own experiences, feelings and emotions, how they accepted and coped with their situations, and how they were viewed in the outer world after being told that their mothers were HIV-positive.

# Now I know... The painful truth

The stories which participants told revealed that upon hearing for the first time about their mother's HIV status, they experienced shock, pain and fear. When people discover their HIV/AIDS-positive status or that of their loved ones for the first time, they experience shock (Black, 2009; Nashandi, 2002; Roman, 2006; Shebi, 2006).

My mom told me about her HIV status herself. She told me over the phone. But first time I heard I could not believe it because my mom was pregnant with my small brother. (Participant 2, 14 years old)

I was shocked because I hear other people say if you have HIV/AIDS you gonna die (Participant 4, 15 years old)

The fact that participants were shocked indicates that they did not expect that their mothers could be HIV/AIDS-positive, because HIV/AIDS is often associated with death. Hence, the situation was shocking when their mothers disclosed their HIV status to them. When an experience is shocking, it often symbolises a turning point in the shocked person's life (Black, 2009; Nashandi, 2002; Roman, 2006; Shebi, 2006). Once the shock of hearing the information for the first time had worn off, participants experienced this feeling as very painful.

As she thought back, Participant 1 described how her mother disclosed that she was HIV/AIDSpositive. She said that she was hurt and saddened by such a disclosure: She called us (the participant and her sister); she sat us down and told us she was HIV positive. I felt so sad. Participant 2 described her heartache and her inability to believe that it was actually real that her mother was HIV-positive: When I first discovered that my mom was HIV positive my heart was broken, I could not believe it. For a week, participant 3 was challenged to absorb the news about her mother's HVAIDS-positive status. She said she could not express her feelings of disappointment to her mother. She was silenced for a week by her emotional pain. Shedding tears remained the only way she could express how hurt she felt: I cried when I discovered that my mom is HIV positive, after that I could not say a word to her, for about a week I could not engage in a conversation with her. Participant 4 also described how he was hurt to the point of not knowing how to express his feelings: At first I was sad. I did not know how do I, how can I talk about that. Participant 5 looked back and described how her mother disclosed her HIV/AIDS-positive status. She was not only affected by discovering her mother's HIV infection, but also by the emotions expressed by her mother: She called me and my sister and told us she is HIV/AIDS

positive. I felt very bad. She was crying as she was telling us. Participant 6 expressed that discovering his mother's HIV/AIDS status caused him pain: It was so painful when I discovered about my mom's HIV/AIDS status. I thought she will leave me (through death).

The participants expressed emotional distress such as hurt and pain with regard to their mothers' HIV/AIDS-positive status. Adolescents' emotional distress in the context of HIV/AIDS has also been reported by other studies which examined their psychosocial well-being (Bauman et al., 2006; Carstens, 2003; Linsk & Mason, 2004; Strode & Barret-Grant, 2001). The narrative tone expressed in participants' responses reflected painful emotions, sadness and disappointment. Parents and children form an interdependent and interactive social unit (Rotheram-Borus, Stein & Lin, 2001). When parents become infected with HIV, the entire family is affected (Gunther et al., 1998).

## Fear

Fear is "being worried or frightened that something bad might happen or might have happened" (Woodford, 2007: p. 261). The fear of HIV/AIDS is attributed to its devastating and debilitating social, psychological, emotional, physical and economic effects (Soskolne, 2003; Theron, 2005). Adolescents affected by HIV/AIDS experience intense fear of losing a parent through death caused by the epidemic (Gunther et al., 1998).

I hear other people say if you have HIV/AIDS you gonna die. And now that made me sad (Participant 4).

It was difficult; I thought she will die early (Participant 5).

I thought she will leave me (through death) [Participant 6).

Thoughts of the death of a parent, especially a mother, are distressful as they can lead to feelings of anxiety and depression if not properly dealt with (Black, 2009; Deacon & Stephney, 2007; Gunther et al., 1998). The situation of Participant 4 was intensified by the socially constructed beliefs and interpretations regarding HIV/AIDS by people in the community, (*I hear other people say if you have HIV/AIDS you gonna die*). These beliefs and interpretations are usually based on ideas, and not

on factual information (Speed, 1991). Such socially constructed points of view can cause psychological distress in the lives of people affected by HIV/AIDS. The fear of death has been captured in research findings regarding people infected and affected by HIV/AIDS (Black 2009; Jonson, 2009; Nashandi, 2002; Roman, 2006; Shebi, 2006; Soskolne, 2003).

# Now I have to cope ...

"Coping" refers to "a person's constantly changing cognitive and behavioural efforts used to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person" (Rose & Clark-Alexander, 1999: p. 337). Through telling their own stories, participants outlined their coping mechanisms. A sense of surviving was expressed as imagery in coping with living in households with HIV/AIDS-positive mothers. The sense of coping was enhanced when participants witnessed their mother's ability to cope with her own illness. This finding concurs with reports provided in the study conducted by Rotheram-Borus, Stein and Lin (2001) regarding adjustments of adolescents whose parents had HIV/AIDS.

My mom then bought a house. Then I went to stay with my mommy and to look after her. I watch the time for her to take her medicine. I must make her food before she take her medicine. I must sort out her bed to make it comfortable for her to sleep. After that I can go to play outside. I survive just to be with my mom. When I go to play I'm not scared to tell the people that my mom is sick of HIV/AIDS. When she goes to the clinic, I'm not going to school; I go with her to the clinic. So I feel better. (Participant 2, 14 years old)

Participant 2 felt very secure when she moved in with her mother. Having to perform activities that reflected both care and support of her mother seemed to have brought a sense of bonding and fulfilment into the participant's life. The motherdaughter bonding has been mentioned as one of the effective methods in enabling coping for adolescent girls affected by HIV/AIDS of the mother (Lee, Lester & Rotheram-Borus, 2002). A child's narrative tones are affected and shaped by "the achievement of secure or insecure attachment relationships during the early childhood years" (Crossley, 2000a: p. 89). I was happy because after I heard about her status she told me, "don't worry, I'm gonna be alright". (Participant 4, 15 years old)

My mom disclosed her HIV/AIDS status herself. I felt so bad. But when finished telling me, she also explained more about what HIV/AIDS, to give me a better understanding. (Participant 6, 14 years old)

Participants 4 and 6 indicated that their coping ability was enhanced through HIV/AIDS information provided to them by their mothers. Parental and social supports could effectively be used by adolescents as coping mechanisms (Deacon & Stephney, 2007; Lee, Lester & Rotheram-Borus, 2002; Lyon & D'Angelo, 2006). The social support can be emotional, cognitive and instrumental (Shebi, 2006: p. 17), and can be given through, but not limited to, the provision of relevant and resourceful HIV/AIDS information. Cognitive support can be "in a form of knowledge, information and advice" (Nkosi, 2006: p. 94).

# And now laccept ...

Acceptance, according to Long (Nkosi, 2006: p. 81), "is the underlying belief and attitude that is worthy of self-respect and the corresponding attitude of respect for others' capability to be self-responsible". Narratives show that participants were able to accept and live with the situations of their mothers without being judgemental. Hence, acceptance means a conscious choice to fully acknowledge and respect another person's worthiness without questioning his or her capability to be selfresponsible.

Just for those (children) who their mothers have HIV they have to take it. They have to take care of their mothers and enjoy it (Participant 2).

We do speak and that's nice yes, however I do get that feeling that she's not exactly what I expect of her, but she will remain my mother and nothing will change that (Participant 3).

My grandmother and I have accepted my mom's situation. My grandmother understands because when my mom disclosed she also explained to her – more about HIV/AIDS. My grandmother said to my mom that she is still her child and nothing will ever change that (Participant 6).

# When others know...

Discrimination, according to Manser and Thompson (1999: p. 369), often occurs on behavioural and practical levels and it refers to the "unjustifiably different treatment given to different people or groups." In the context of this study, discrimination is discussed with regard to the situation of adolescents affected by HIV/AIDS through the mother's status.

Participant 1 explained that she was discriminated against because of her mother's HIV/AIDS status; her friends stopped visiting her. It shows that the participant's friends were influenced by their mothers. These friends' mothers were aware of the HIV/AIDS- positive status of the participant's mother. The friends' mothers also used to be friends of the participant's mother, but deserted her after discovering that she was HIV/AIDS- positive. Hence both the participant and her mother experienced discrimination:

My friends stopped coming to visit me. Their mothers told them about my mother's situation as they themselves used to be my mother's friends and knew about her status. Thus we did not get along anymore.

Participant 2 described how she witnessed her mother being treated unfairly because of her HIV/AIDS-positive status.

My uncle, when he saw my mom going to the toilet, he would do bad things. He would wait for my mom to come out of the toilet, and then he would take a toilet paper and wipe off the toilet even though there was nothing to wipe off...even when my mom eats with a spoon. My uncle said she must have one spoon to use.

Participant 6 emphasised that his family received fair treatment from the people in the community. He further explained that the fair treatment was based on the fact that people had a clear understanding that there could be a reasonable cause of HIV infection:

In the community people treat us very well because they know that AIDS does not just infect a person. They don't gossip about us, they know that what my mom has she did not choose to have.

Through their stories, participants 1 and 2 expressed

negative feelings with regard to experiencing discrimination. As with previous studies, the narratives highlight that when adolescents live in a home where a parent has HIV/AIDS discrimination, by family members, friends and relatives, is encountered (Campell et al., 2005; Francis & Francis, 2006; Lyon & D'Angelo, 2006). Furthermore, adolescents are marginalised because of socially constructed beliefs about HIV/AIDS (Black, 2009; Nashandi, 2002; Roman, 2006). Such negatively constructed interpretations of the HIV/AIDS pandemic also produce stigmas (Deacon & Stephney, 2007; Nashandi, 2002). The stories in this study suggest that individuals, who discriminate, are uninformed about HIV/AIDS. It seems that a lack of knowledge causes people to stigmatise and discriminate against people infected and affected by HIV/AIDS. Similar findings have been reported by Simbayi, Kaseje and Niang (2007).

Conversely, participant 6's story indicated that they were accepted by friends, relatives and people in the community. These people were assumed to have clear knowledge and understanding of HIV/AIDS transmission and prevention, and could focus on providing emotional support to individuals affected by HIV/AIDS. This finding concurs with studies conducted by Jonson (2009) and Shebi (2006) which highlight that people with clear knowledge and understanding of HIV/AIDS are more supportive towards people infected and affected by HIV/AIDS.

# Rejection

Adolescents affected by HIV/AIDS may experience social rejection, which has a tendency to reduce their sense of self-worth (Black, 2009; Deacon & Stephney, 2007; Jonson, 2009). The stories of these participants revealed the sense of rejection which they experienced when their mothers were found to have HIV/AIDS.

When my friends rejected me I felt so hurt because it was obvious they were judging me (Participant 1).

Research indicates that when adolescents affected by HIV/AIDS experience unfair and unjust treatment, the situation creates anxiety, stress, loneliness and depression (Molassiotis et al., 2002; Tompkins & Wyatt, 2008). Psychosocial studies also show that experiences of social behaviour may have a negative impact on the cognitive functioning of the affected adolescents (Deacon & Stephney, 2007).

# School attendance and performance

The participants spoke about how they managed school-related challenges. The narrative accounts of Participants 1, 2 and 5 suggest that their school attendance was disrupted by various factors. Participant 1 did not have lunch at school owing to a lack of money. Participant 5 had to leave early from school because her mother needed close attention and monitoring due to her illness. Participant 2 had to miss school in order to accompany her mother to the clinic. The irregular school attendance was a potential danger for low school performance and dropping out of school (Black, 2009; Linsk & Mason, 2004; Scott, 2004).

Participant 1 indicated that it was not her educational performance that was affected by her mother's situation, but rather her school attendance: At school I did not attend so well anymore because I sometimes did not have money to buy food for lunch, and I was not used to that.

Participant 5 expressed her lack of stability regarding school attendance because of her mother's illness. In addition, her educational performance was affected as she battled to concentrate while writing tests: Sometimes I have to leave early at school because my mother would be very sick. My school performance dropped when I write tests my mind is always preoccupied with my mom's conditions.

Participant 2 explained that even though her mother's situation had affected her, she needed to be able to concentrate at school. She expressed her fears of not performing successfully at school:

The situation has affected me, but when I'm at school I have to forget that to concentrate on my books because I was thinking I was going to fail this year, but I did not fail. When she goes to the clinic, I'm not going to school; I go with her to the clinic.

Another set of narratives indicated that participants 4 and 6 were doing well at school and had no school interruptions. Participant 3 indicated that although her mother's situation affected her, she nevertheless maintained her performance. The extracts of Participants 4 and 6 demonstrated that their school performance was not affected by their mother's illness. This may suggest that boys were coping better with the situation they were experiencing than girls (Bauman et al., 2006; Francis & Francis, 2006)

Participant 3 emphasised that her level of performance dropped due to her mother's situation: *At school it has affected me just a bit, my performance is not that bad.* 

Participants 4 and 6 explained that they managed well with regard to educational performance:

I always do my school work and I don't have any problem. My school performance is perfect. (Participant 4)

My mom's situation has not affected me at school. I have realised that when I passed all my tests. (Participant 6, 14 years old)

### Poverty

The HIV/AIDS epidemic is more intense in poor communities, as it has been found that most people living in poor communities are HIV/AIDS-positive (Black, 2009; Francis and Francis, 2006; Scott, 2004). When one or more family members are infected with HIV, the income of the family may drop (Black, 2009).

Her (mother's) sister will try to comfort me and she will give me her own money to buy food because at home we don't have money to buy enough food (Participant 4).

The narrative accounts reflect the financial struggles, which seemed to have worsened with the mother having HIV/AIDS. Poverty can cause distress in the lives of adolescents as it is associated with malnutrition, low level of cognitive functioning, dropping out of school, and committing crime for survival (Scott, 2004; Richter, 2004; Ranchod, 2005; Black, 2009).

## Conclusion

The aim of the present study was to (a) explore the perceptions of and experiences of adolescents living in households where the mother had HIV/AIDS, and (b) to describe the coping mechanisms used by

adolescents in these households. This study contributes to the body of knowledge which can be imparted in terms of development and enhancement of applicable policies and procedures in the area of HIV/AIDS. Through story-telling, the participants shared their personal stories about living in households where their mother was HIV/AIDSpositive. Their stories produced three phases through which they had moved: that of first encountering the information about their mother's status, then coping, and finally showing willingness to accept although they did not full accept their mothers's illness. They demonstrated courage to endure the odds within their situations. Their stories reflected the emotionally challenging situations they faced. However, in the midst of the negative situation, these adolescents had found an inner strength to cope with and endure their situation. The mother's love, support and ability to cope with her own health conditions were the overall secure base on which adolescents felt enabled to cope. Other factors that served as contributing coping mechanisms were in a form of social support provided by friends and other family relatives. As a recommendation, government should implement relevant programmes and support structures, which could also on combating stigma and discrimination. This implementation could involve relevant NGO's, NPO's, FBO's and other stakeholders. Appropriate interventions are additionally needed to strengthen and support the affected families in terms of emotional and material needs.

#### References

- Bauman, L J., Foster, G., Silver, E. J., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. Vulnerable Children and Youth Studies, 1 (1), pp. 56-70.
- Black, L. A. (2009). Adolescents' experiences of Living with HIV and AIDS. Unpublished Master's thesis, University of Witwatersrand, Johannesburg, South Africa.
- Carstens, A. (2003). What lay illness narratives reveal about AIDS-related stigmatization: Communicare, 22 (2), pp. 1-24.
- Campell, C., Foulis, C. A., Maimane, S., & Sibiya, Z. (2005). I Have an Evil Child at My House: Stigma and HIV/AIDS Management in a South African Community. American Journal of Public Health, 95 (5), pp. 808-815.
- Chadwick, R. J. (2001). Selves colliding with structure: The discursive construction of change and non-change in narratives of rape crisis volunteers. Unpublished Master's

Thesis, University of Cape Town.

- Corrigan, P. W., Larson, J. E., & Rusch, N. (2009). Self-stigma and the "why try" effect: Impact on life goals and evidence based practices. World Psychiatry, 8 (2), pp. 75-81.
- Crossley, M. L. (2000a). Introducing narrative psychology: Self, trauma and the construction of meaning. Milton Keynes: Open University Press.
- Crossley, M. L. (2000b). Narrative psychology, trauma and the study of self/identity. Theory and Psychology, 10 (4), pp. 527-546.
- Davids, A., Letlape, L., Magome, K., Makgoba, S., Mandivenyi, C., Mdwaba, T., Ned, N., Nkomo, N., Mfecane, S., & Skinner, D. (2006). A situational analysis of orphans and vulnerable children in four districts of South Africa. Cape Town, SA: HSRC Press.
- Davies, M. I. (1997). Shattered assumptions: Time and the experiences of long-term HIV positivity. Social Science and Medicine, 44 (5) pp. 561-571.
- Deacon, H. & Stephney, I. (2007). HIV/AIDS, stigma and children: A literature review. Cape Town, SA: HSRC Press.
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. Social Science and Medicine, 50, pp. 605-617.
- Francis, D., & Francis, E. (2006). Raising awareness of HIVrelated stigma and its associated prejudice and discrimination. South African Journal of Higher Education, 20 (1), pp. 44-45.
- Gunther, M., Grandles, S., Williams, G., & Swain, M. (1998). A place called HOPE: Group psychotherapy for adolescents of parents with HIV/AIDS. Child Welfare, 77 (2), pp. 251-271.
- Hayden, L. C. (1997). Illness and narrative. Sociology of Health & illness, 19 (1), pp. 48-69.
- Jonson, K. (2009). Experiences of HIV Infected and Affected Adolescents of the Support Provided by Reach Out Mbuya Parish HIV/AIDS Initiative, Kampala, Uganda. Karalinska Institute, Stockholm, Sweden. IHCAR-Department of Public Health Services. Division of International Health.
- Lazarus, R. S., & Folkman, S. (1980). Stress, appraisal and coping. New York, USA: Springer.
- Lee, M. B., Lester, P. & Rotheram-Borus, M. J. (2002). The relationship between adjustment of mothers with HIV and their adolescents daughters. Clinical Child Psychology and Psychiatry, 7 (1), pp. 71-84.
- Linsk, N. L., & Mason, S. (2004). Stresses on grandparents and other relatives caring for children affected by HIV/AIDS. Health & Social Work, 29 (2), pp. 127-136.
- Lyon, E. M., & D'Angelo, L. J. (2006). Teenagers HIV and AIDS: The insights from youths living with the virus. Westport, Conn: Praeger Publishers.
- Manfred, J. (2005). Narratology: A Guide to the Theory of Narrative. Retrieved May 11, 2009 from http://www.uni.koeln.de/name02/pppn.htm.

Manser, M., & Thompson, M. (Eds). (1999). Combined Dictionary

Thesaurus. Edinburgh: Chambers.

- Melnick, M. (2001). An investigation of the coping strategies of care givers providing home-based care for people with advanced HIV infection. Work in progress. In: Bak, N. & Vergnani, T. (eds.). Proceedings of the Multi-Disciplinary Conference on HIV/AIDS. UWC, 3 November. South Africa: pp. 74-85.
- Molassiotis, A., Callaghan, P., Twinn, S. F., Lam, S. W., Chung, W. Y., & Li, C. K. (2002). A Pilot Study of the Effects of Cognitive-Behavioral Group Therapy and Peer Support/Counseling in Decreasing Psychologic Distress and Improving Quality of Life in Chinese Patients with Symptomatic HIV Disease. AIDS Patient Care and STD's, 16 (2), pp. 83-96.
- Nashandi, J. C. N. (2002). Experiences and coping strategies of women living with HIV/AIDS: Case study of Khomas region, Namibia. Unpublished Master's thesis, University of the Western Cape, Bellville, South Africa.
- Nkosi, L. A. (2006). Narratives of pregnant teenagers about reproductive health care services in a clinic in Gauteng Province. Unpublished Master's Thesis. University of South Africa.
- Polkinghorne, D. E. (1988) Narrative Knowing and the Human Sciences. Albany: State University of New York Press.
- Ranchod, B. (2005). HIV/AIDS and its impact on children in South Africa: 4th World Congress on Family Law and Children's Rights Presentation. (Retrieved August 18, 2007 from www.childjustice.org/docs/ranchod2005.pdf.
- Richter, L., Manegold, J., & Pather, R. (2004). Family and community interventions for children affected by AIDS. Cape Town, SA: HSRC Press.
- Richter, L. (2004). The Impact of HIV/AIDS on the Development of Children. (ISS Monograph No. 109), 9 – 31. Available from: http://www.iss.co.za/pubs/Monographs/No109/Chap2.pdf
- Roman, G. S. (2006). An exploration of the stigma experienced by women who are living with HIV/AIDS. Unpublished Master's thesis, University of the Western Cape, Bellville, South Africa.
- Rose, M. A., & Clark-Alexander, B. (1999). Coping styles of caregivers of children with HIV/AIDS: Implications for health professionals. AIDS Patient Care and STDs, 13 (6), pp. 337-355.
- Rotheram-Borus, M. J., Stein, J. A., & Lin, Y. Y. (2001). Impact of parent death and intervention on the adjustment of adolescents whose parents have HIV/AIDS. Journal of Consulting and Clinical Psychology, 69 (5), pp. 763-773.
- Sabrin, T. R. (1986) Narrative psychology: The storied nature of human conduct. New York, USA: Praeger.
- Scott, N. (2004). What does the future hold? Reclaiming Children and Youth, 12 (4), pp. 201-202.
- Shebi, M. M. (2006). The experiences and coping strategies of HIV/AIDS primary caregivers within two disadvantaged communities in the Western Cape metropole. Unpublished

Master's thesis, University of the Western Cape, Bellville, South Africa.

- Simbayi, L. C., Kleintjes, S., Ngomane, T., Tabane, C. E. M., Mfecane, S., & Davids A. (2006). Psychosocial issues affecting orphaned and vulnerable children in two South African communities. Cape Town, SA: HSRC Press.
- Simbayi, L. C., Kaseje, D., & Niang, C. I. (2007). Overview and regional progress of current SAHARA projects in sub-Saharan Africa. Exploring the challenges of HIV/AIDS. Cape Town, SA: HSRC Press.
- Soskolne, T. (2003). Moving beyond the margins: A narrative analysis of the life stories of women living with HIV/AIDS in Khayelitsha. Retrieved August 18, 2007 from http://www.uct.ac.za/depts/cssr/pubs.html.
- Statistics South Africa. (2009). Mid-year population estimates, South Africa. (Statistical release P0302). Pretoria, South Africa.
- Strode, A., & Barret-Grant, K. (2001). The role of stigma and

discrimination in increasing the vulnerability of children and youth infected with and affected by HIV/AIDS. Arcadia, SA: Save the Children (UK).

- Theron, L. C. (2005). Educator perception of educators' and learners' HIV status with a view to wellness promotion. South African Journal of Education, 25 (1), pp. 56-60.
- Tompkins, T. L. & Wyatt, G. E. (2008). Child Psychosocial Adjustment and Parenting in Families Affected by Maternal HIV/AIDS. Journal of Child and Family Studies, 17, pp. 823-838.
- UNAIDS. (2009). AIDS epidemic update South Africa. Geneva: UNAIDS.
- Van Niekerk, M. (2003). The unheard stories of adolescents infected and affected by HIV/AIDS about care and/or the lack of care. Practical Theology in South Africa, 18 (3), pp. 109-120.
- Woodford, K. (2007). Cambridge Learner's Dictionary: Third Edition. Cambridge, UK: Cambridge University Press.