A phenomenological study of the experiences of adolescents following maternal HIV-disclosure

by

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Declaration

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety/ in part submitted it at any university for a degree.

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Abstract

Maternal HIV-disclosure to an adolescent is a controversial issue especially when considering the suitable time and context in which disclosure should take place. Furthermore there have been other considerations such as the adolescent's emotional maturity as well as gender issues which have played a role in regards to determining whether the adolescent would be able to understand and cope effectively post-disclosure. These considerations formed the basis of this study's aim and objectives which primarily focused on taking into account the developmental aspects apparent in the adolescent phase. These include adolescent's relations with their mother, their peers and the meaning attached to having an education and career in their lives. For purposes of this study it was deemed important to actually explore with the adolescent's the meaning they uphold pertaining to maternal HIV-disclosure. This differs from previous research which has focused predominantly on accessing adolescent's experiences via their parents and in particular, their mothers. Data of only three participants was included following in-depth interviews being conducted. Data was analysed via Interpretive Phenomenological Analysis (IPA) which enabled an enhanced understanding and meaningful interpretation of the adolescent's experiences following maternal HIV-disclosure. From the findings it became apparent that most concerns had already been addressed and were similar when compared to previous research that had been conducted. However one notable different finding was that instead of adolescent's acting in ways that would lead to them self-sabotaging their lives they instead portrayed themselves to be living in a responsible manner. It became apparent rather that it was the adolescent's mother rather that became more inclined to engage in self-sabotaging behaviours.

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“There is a time for everything and a season for every activity under the heavens”

(Ecclesiastes 3:1)

I would like to thank God for having blessed me over the years with such a beautiful life. I believe that it is through Him that the timing of this project was perfect.

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1. Chapter One: Background to study

1.1 Introduction

In this chapter the study is presented vis-à-vis the experiences of adolescents following maternal HIV-disclosure. An elaborate account regarding the incidence and prevalent rates are included thus providing a comprehensive understanding of the impact of HIV/AIDS in the lives of affected adolescents.

The epidemiology will first be presented followed by the rationale, aims of the study and finally the research questions.

1.2 Epidemiology:

1.2.1 International statistics

HIV/AIDS was first reported over 30 years ago and has subsequently been one of the leading causes of death in the world (Regional statistics, 2011). Initially living with the disease was drastically feared as there was no treatment regime and interventions to assist in combating the fatal effects of the disease (Regional statistics, 2011).

It has been estimated that globally there has been 34 million people at the end of 2011 that were living with HIV. It was further explained that from this figure, an estimated 0.8% of adults that are aged between 15 and 49 are living with HIV. However different regions and countries in the world account for the different estimates that become generated (UNAIDS, 2012).

The total amount of newly infected adults and children has been shown to be decreasing worldwide. It has been shown that when compared to the year 2001, the amount of people that were newly infected in 2011 totalled up to (2.5 million [2.2 million-2.8 million]) which proved to be lower by 20%. The Caribbean has been one of the regions that has had the sharpest declines amounting to 42% since 2001 regarding the number of people that are being newly infected with HIV (UNAIDS, 2012). However, this positive trend has not impacted in the same manner in other regions. For example, the Middle East has experienced significant increases totalling up to 35% of newly infected people. This figure means that the increase has been from 27 000 (22 000-34 000) to 37 000. Moreover Eastern Europe as well as Central

Asia have also showed an increase in their HIV incidence rate from the late 2000s. This has been despite the fact that they have maintained stable incidence rates over the past years (UNAIDS, 2012). Hence this proves that although HIV globally is generally declining, there are still many countries that have high incidence rates.

1.2.2 Sub-Saharan African statistics

Sub-Saharan Africa has been known to be mostly affected by the HIV/AIDS epidemic. An estimated number of one in every 20 adults - amounting to 5% - is deemed to be living with HIV. On a broader scale this implies that this percentage accounts for 69% of people worldwide that are living with HIV. Other regions that are also bearing the brunt of such high rates of people living with HIV, include the Eastern Europe and Central Asia which meant that 1% of adults were living with HIV (UNAIDS, 2012). Between the year 2001 and 2011 it has been evident that Sub-Saharan Africa's incidence rate has decreased. In 2001 the incidence rate was recorded to be 2.4 million (2.2 million - 2.5 million) of people infected by the illness. In contrast in 2011 the incidence rate was 1.8 million (1.6 million - 2 million) which equalled to a total of 25% decrease (UNAIDS, 2012). However, this significant decrease risks being unnoticed due to the fact that Sub-Saharan Africa accounted for a total of 71% of children and adults that were newly infected with HIV in 2011. Women of child bearing age were the most infected persons. Children were mostly infected via mother-to-child transmission of the illness (UNAIDS, 2012). The high percentage of newly infected women and children has been viewed as an obstacle as it seems that the preventative measures that have been implemented in the past years has not yet made much impact.

1.2.3 South African statistics

Since this study is located within South Africa, the following statistics have been included as they provide pertinent information about the study's contextual background. It has been evident that there has been a noticeable increase in the prevalence rates of people living with HIV in South Africa between the year 2001 and 2011. That is, the estimates range from 4.21 million of people in 2001 and 5.38 million in the latter year. In 2011, an estimated amount of 10.6% of people was HIV positive. Furthermore an estimate of one-fifth of women within their reproductive ages is living with HIV. This entails that women aged between 15 and 49 have approximately a prevalence rate of 19.4% (UNAIDS, 2012). This information corresponds with the high percentage of adults and children that have been identified to be

living with HIV. It has been argued that women as opposed to men are at an increased risk of contracting HIV during sexual intercourse. Specifically, it is young women aged between 15 and 24 that have a prevalence rate that is twice more than men's prevalence rate (UNAIDS, 2012). This implies that since women are at an increased chance of contracting HIV, this also increases their children's susceptibility of contracting HIV. The eastern and southern region of South Africa confirm that mother-to-child transmission of the illness is increasing as over 400 children below 15 years have died from AIDS-related infection (Progress Report, 2011). Factors making it more likely for women to have increased prevalence rates of HIV include the reality of the social, legal and economic disadvantages that confront women (Progress Report, 2011; van der Linde, 2013). Also of note is that between 10% and 28% of children below the age of five have died due to HIV-related illnesses in the year 2010 (Progress Report, 2011).

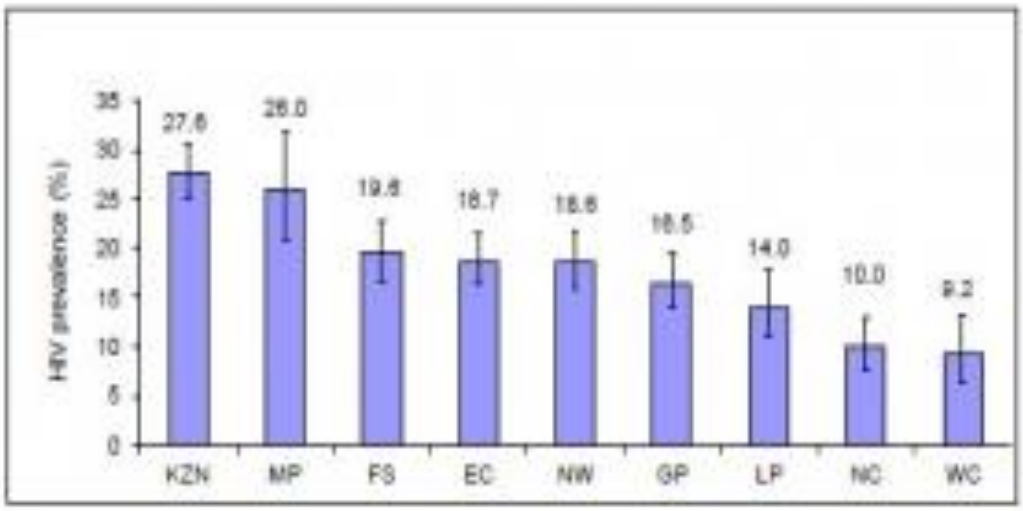
The fight against children becoming infected with HIV is thriving on as is evident in antiretroviral regimes that have been implemented to prevent the transmission of the virus to the baby (Progress Report, 2011). The number of pregnant women receiving antiretroviral treatment increased from 16% in 2006 to 64% in 2010 (Progress Report, 2011). This information is important for the present study as it gives South Africans hope about being provided with a treatment regime. Other issues which are not catered for and therefore not thoroughly addressed by the medical intervention are, however, raised. For example these include psychological and social issues which may specifically entail access to services and support structures from family members and community at large which is important once a person is infected with the illness. However, the huge unequal distribution of the treatment regime between and within countries is concerning. Some countries have managed to receive adequate coverage of the regime reaching rates that are more than 95%. These countries are Botswana, Namibia, South Africa and Swaziland (Progress Report, 2011).

In South Africa HIV/AIDS infection rates differ across provinces. KwaZulu-Natal has the highest percentage of people living with HIV/AIDS which accounts for a proportion of 15%. KwaZulu-Natal is then followed by Free-State, Mpumalanga and the North West respectively. The Western Cape with its 5% of proportion living with HIV/AIDS accounts for the lowest proportion (Health 24, 2012).

HIV/AIDS prevalence rates by province for people aged between 15 and 49 years differ across provinces in South Africa. Out of the 5.258 million South Africans that are infected

with HIV/AIDS, figure two below highlights these notable differences. Eastern Cape is the fourth highest out of the nine provinces to have high prevalence rates which highlights the ongoing challenges encountered in this province in regards to people living and affected by the virus. Hence this research study aims is to explore into further detail the impact experienced by adolescent's affected by the illness (van der Linde, 2013).

Figure 2: HIV prevalence by province (15 – 49 years) South Africa 2012



1.2.4 Grahamstown statistics

It has been depicted that within the Makana Municipality wherein Grahamstown is located, adults between the age group of 15-49 years were presenting with a prevalence rate of 15.5% in the year 2005 (Makhubela, Parker, & Birdsall, 2007). However the prevalence rate was higher for 15-17 year olds as it reached an estimate of 17%, also in 2005. When referring to figure 2 above it becomes clear that the prevalence rate has increased and it seems that young people's prevalence rate contributed the most when compared to other age groups. It has argued that low socioeconomic status as well as poverty, low perceived risk of getting HIV, intergenerational as well as transactional sex have been postulated reasons that may account for the prevalence rate (Second National HIV Communication Survey, 2009). Estimates from the public sector clinics has further depicted that there are approximately 5000 people who are HIV positive, 600 of which depicted to be in the late stages of infection. Due to these figures it has been inferred that there were 500-600 children orphaned due to AIDS related death (Makhubela, Parker, & Birdsall, 2007).

Despite the increasing number of people living with HIV/AIDS in South Africa, it is hoped that through protective measures, for example people practicing protected sexual intercourse, that in particular, the percentage of women who have been diagnosed with HIV and those attending (public) antenatal clinics is expected to decrease from 29% to 25% (Health 24, 2012).

1.3 Rationale

Based on the above mentioned epidemiological evidence, it is apparent that women and children are the most affected. Maternal HIV-disclosure is a major challenge as evidenced by the adolescent's significant emotional and behavioural problems that they have presented with (Jurkovic, 1997).This essentially implies that disclosure is not an easy process and therefore the consequences should not be taken for granted. However, it has been factors such as the quality of the parent-child relationship which have significantly contributed towards playing a protective or risk factor regarding whether the child presents with internalizing/ externalizing symptoms (Ormel, Oldehinkel, Ferdinand, Hartman, Winter, Veenstra, Vollebergh, Minderaa, Buitelaar, & Verhulst, 2005). Furthermore with the often increased responsibilities that come into play following maternal HIV-disclosure there have been contesting views on whether the responsibilities (and tasks) become pathological or whether it is something that fits well into certain cultural norms (Tompkins, 2007).

In many instances it has been the case that being infected or affected with HIV/AIDS is compounded with others stressors such as poverty. Poverty is a major concern in South Africa as it affects 85% of Africans as opposed to 87% of white South Africans who continue to live in the middle and upper class categories (Goldman Sachs Report, 2013). The lack of basic services (included are the lack of NGOs) such as hospices or mobile clinics may necessitate that children start working at a young age (before finishing school). However due to their lack of skills (due to age), the kind of work may itself pose a high health risk for example, working as a sex worker. This implies that such decisions may be influenced by the impending need to fulfil social needs, even though this could harm one's psychological wellbeing. Important needs such as the right of being educated may end up being neglected (Foster, & Williamson, 2000). Therefore these are some of the difficulties encountered by adolescents who are living in low socio-economic conditions and are affected by HIV/AIDS.

Unmet psychological needs and affected adolescents' attempt to be well have led to efforts of not exposing their vulnerability by concealing feelings of sadness, anxiety and hopelessness has been a strategy of protecting oneself from the comments and reactions deemed to have a stigmatizing impact. It is a concern as stigma is not only communicated and felt amongst people in the community but can also be felt within family members as well. The latter has generally been more prevalent in relation to extended family members or relatives.

Furthermore the effects of being stigmatised seem to pose a threat to one's understanding and confidence in terms of how they start perceiving themselves (Foster, & Williamson, 2000). The pressure and need to fit in society under these circumstances is evident that there is a need amongst children affected by HIV to reinforce that they too are normal children in society (Foster & Williamson, 2000).

The pressure to fit in and not feel different from other adolescents is a challenge that is perpetuated by the ongoing increasing rates of HIV/AIDS infection which has been depicted to be mostly evident amongst women within child-bearing age (Progress Report, 2011). These feelings of insecurity amongst adolescents may be further perpetuated when for instance their parent/s die from AIDS related illnesses. Literature suggests that in these circumstances children may end up heading households unsupervised. However if their grandparents are still alive and willing to partake in their upbringing, the latter become involved in raising them (Moffet, 2007). Such experiences set the affected adolescent apart from other adolescents who are not experiencing such difficulties and makes their need to be 'normal' an understandable and accurate depiction of their loneliness in their experiences, especially from other adolescents.

Since this research study is centred particularly on adolescents that are affected by HIV/AIDS it is of concern whether the distinct aspects of the adolescent's phase which include their gender, career/ education, peers and other significant relationships (Erikson, 1950) and their relationship with the primary maternal figure exacerbate or make it better for the adolescent to cope with stressors in their lives.

Concerning is still the disproportionate increased levels of women infected with HIV as compared to men as evidenced within the age group of 15-24 year olds (Progress Report, 2011). This disparity has not only been marked by women's physiological vulnerability but increasingly also from disadvantages pertaining to severe social, legal and economic factors

(Progress Report, 2011). Correspondingly it has been the case that children also become at an increased risk rate of contracting the virus during pregnancy, delivery or through breast feeding (Progress Report, 2011). Therefore this poses the question of who then becomes involved in the upbringing and in taking care of children when for instance; their parents pass away due to the virus.

From this above mentioned issues, it is thus evident that the research study is important on two levels. Firstly, there is limited research pertaining to maternal HIV disclosure in the African context hence this research study has deemed it an opportunity to explore more of the adolescent's perspective (Rochat, Mkwanazi, & Bland, 2013). Furthermore this research has been conducted for practical issues meaning that by exploring how it is that adolescents are affected; supportive interventions tailored for adolescents can hopefully be looked into. Secondly, this research is conducted for theoretical reasons meaning that through consulting with previous theoretical work, an enhanced understanding and meaning can be applied in understanding the phase encountered in adolescents.

1.4 Aim and objectives of the study

Following from the above rational, the present study aims to explore how does maternal HIV-disclosure impact on adolescent's development with particular reference to:

- The relationship with their mothers and the kinds of roles expected of them
- Peer and other significant relationships
- Their educational or career development

The above objectives are explored in relation to the post-maternal HIV-disclosure experiences. Due to the exploratory nature of the study, it was deemed more appropriate not to predetermine the results. Therefore this implies that the findings in the study have been qualitatively grounded as data has been analysed phenomenologically. Specifically it was deemed appropriate to analyse data using Interpretive Phenomenological Analysis (IPA) as in-depth exploration of adolescents' experiences would permit meaningful interpretations of the adolescents' narratives (Smith & Osborn, 2008).

1.5 Definition of term

Adolescence

"The period of development from the onset of puberty to the attainment of adulthood, beginning with the appearance of secondary sexual characteristics, usually between eleven and thirteen years of age, continuing through the teenage years, and terminating legally at the age of the majority, usually eighteen years of age" (Coleman, p. 14, 2009).

2. Chapter two: Literature Review

2.1 Introduction

This chapter is organized into two main areas which is the psychological and social issues. The psychological issues which will be discussed first entail: parentification, spousal roles and role reversal significantly; maternal disclosure, changing maternal identity and the impact on the adolescent, stigma sexual vulnerability. Social issues include: gender roles; peer and other significant relationships as well as career and/educational development. Furthermore this chapter reviews literature on the experiences of adolescents following maternal HIV-disclosure. The review provides a comprehensive and basic understanding pertaining to the various areas of an adolescent's life that can be impacted upon. It also raises awareness about the vulnerable situations that the adolescent may end up being exposed to, of which others may be preventable. Furthermore it raises awareness regarding the phase of life that the adolescent is currently experiencing therefore making more meaning to the behaviour and thoughts about particular experiences that they encounter.

2.2 Psychological challenges faced by adolescents

2.2.1 Parentification, spousal roles and role reversal.

Despite the different socio-cultural contexts in which parentification, spousal roles as well as role reversal may take place and the consequences that have been delineated following maternal HIV-disclosure, it has been evident that the nature of the adolescents and maternal relationship is of important concern (Palin, Armistead, Clayton, Ketchen, Lindner, Kokot-Louw, & Pauw, 2008). It has been the case that when there is a better parent-child relationship which may include qualities such as adequate emotional support, open communication, honesty and genuine love, chances of the child/adolescent becoming

distressed become less. For example, chances of the adolescent suffering from internalizing and/externalizing symptoms becomes significantly reduced. This too has been explained by the Stress-Buffering Hypothesis which posits that it is the positive elements within the adolescent-mother relationship that play a protective factor as this mostly buffers against externalizing challenges (Jones, Foster, Zalot, Chester, & King, 2006).

However, it should be noted that the possibility of the child/adolescent displaying internalizing behaviour such as anxiety, symptoms of depression and presenting with somatization problems. In other cases externalizing symptoms which include behavior that is aggressive and often disruptive has been apparent as it has been documented that HIV-disclosure can be an emotionally intense and difficult process (Ormel, Oldehinkel, Ferdinand, Hartman, Winter, Veenstra, Vollebergh, Minderaa, Buitelaar, and Verhulst, 2005).

It often seems like these terms (parentification, role reversal and spousal roles) are frowned upon. This has been largely due to the often strenuous and unsupportive environments in which children/adolescents have been expected to carry out certain roles. For instance, this has been indicated by the terminology used to refer to parentification as it has been known to be indicative of a pathological parent-child role changes which is deemed to be destructive to the child's/ adolescent's development. Moreover it has been seen to be destructive in adolescent's relationships with their peers as it has been seen to impede the adolescent's ability to maintain a healthy relationship with their parent (Garber, 2011). However, it has also been indicated that upon maternal HIV-disclosure, the need to care, support one's mother often becomes a sort of natural response (Delaney, Serovich, & Lim, 2008; Qiao, Li, Zhao, Zhao, & Stanton, 2012). Therefore, it seems that children/adolescents are more likely to assume these roles in an attempt to foster their care and hope to their mothers. This then may to a certain extent deviate significantly from the types of implications expected from "parentified" children/adolescents. This has been demonstrated by Murphy (2008) who has argued for the powerful unity often brought by increased communication between child/adolescent and the maternal figure. It seems that it is through these roles that become negotiated following maternal HIV-disclosure that stronger bonds and relationships become enhanced.

It has been argued that the term parentification should not be used to denote some kind of pathology because as has been shown in some instances, roles commonly associated with

"parentification" can actually be a culturally acceptable phenomenon (Anderson, 1999; Chamorro, 2004). Furthermore these roles have been shown to enhance relationships to a certain extent (Tompkins, 2007). This has been true in instances whereby not only did engaging in primary adult responsibilities benefit the child/adolescent-parent relationship but also significantly lowered any adverse symptoms such as depressive symptoms that were becoming evident in the child (Tompkins, 2007). This is because roles associated with parental tasks are considered to be a normal transitory phase for adolescents within the African context (Anderson, 1999). Meaning that within the western worldview it is considered to be pathological for children to be taking part in parental tasks (Chase, 1999). The understanding around this differs as in the African context it is more likely to be understood as sharing of tasks and responsibilities rather than it being a pathological phenomenon (Chamoruro, 2004).

2.2.2 Maternal Disclosure

Maternal HIV-disclosure to children is reportedly a dynamic process one encompassing "historical and social, contexts that include current knowledge of HIV, belief systems, parent-child relationships, family dynamics, and interactions with health care systems" (DeMatteo Harrison, Arneson, Goldie, Lefebvre, Read & King, 2002 as cited in Murphy, 2008). Hence it is necessary that explanations that include education pertaining to HIV/AIDS as well as physical changes that may occur when one is infected may provide a space wherein the mother may feel comfortable enough to fully disclose their status (Murphy, 2008). It has been the case that maternal disclosure is in most instances an inevitable consequence following the mother's felt moral sense of duty and pragmatic reasons. The latter concerns the mother's inability to hide the noticeable physical changes when the illness is in its advanced stage (Pilowsky, Sohler, & Susser, 2000).

Of note are some considerations that can assist mothers in making appropriate disclosure about their HIV status to their children. Firstly, is taking into account the child's developmental age relative to their developmental stage (DeMatteo Harrison, Arneson, Goldie, Lefebvre, Read & King, 2002 as cited in Murphy, 2008). Secondly, family members may devise a plan which includes having open discussions relating to maternal HIV disclosure that have been depicted to enhance fulfilling family relationships. If open discussions are engulfed by a lack of comfortableness around the issue as well as the lack of

freedom around inquiries then this may likely lead to child confusion and possibly misperceptions regarding their mother's HIV-disclosure (Murphy, 2008). Even though full disclosure is a desirable option, some circumstances make it difficult for this to occur. Since the most common mode of HIV infection is via heterosexual unprotected sexual intercourse this implies that most women are in fact infected by their husbands or committed partners. Therefore this means that the partners were having other sexual relations with other people without possibly taking the necessary precautions to protect themselves (Ostrom, Serovich, & Mason, 2006). Hence explaining the manner in which one contracted the illness can often result in disclosure being pressured or even unplanned (Murphy, 2008). It may be argued that in the short term these kinds of disclosures may put the mother's anxieties at bay as the disclosure is often spontaneous. Nonetheless in the long term Murphy (2008) has found out that unprepared disclosure usually result in mothers regretting the route in which they disclosed their HIV status.

If planned and well considered, maternal HIV-disclosure about maternal HIV status can serve a protective function to children that are disclosed to. This is evident in cases whereby children have reported that after being disclosed to, their self-esteem became enhanced (Murphy, Marelich, & Hoffman, 2002). This may be particularly due to not having stressors that cause one to worry about medication taken by one's mother, which may inevitably lead the child to worry and question the mother's health (Murphy, Steers, & DelloStritto, 2001). Not being informed about the purpose of medication can also result in children/adolescents becoming increasingly concerned and anxious (Murphy, Steers, & DelloStritto, 2001; Murphy, 2008). In addition to this within the family context, if not disclosed to children may start to feel that they are somehow blameworthy for an apparent disordered family environment which may result in them feeling guilty (Murphy, 2008). Moreover Kirshenbaum, and Nevid (2002) have argued that children not disclosed to or those who were told of a nonspecific illness obtained higher problem behavior scores (Kirshenbaum, & Nevid, 2002). In contrast, however, mothers who have disclosed to their children have reported that their children's self-esteem has drastically become negative as they have also noticed increasing levels of their children's interpersonal problems and negative mood (Murphy, & Hoffman, 2002). Reasons for this may be due to the fact that subsequent to disclosing their serostatus the mothers had noted some changes in their children's behavior such as the difficulty of their children's ability to interrelate with them which may be due to

distress caused by the disclosure and the impact it had on the mother's life (Murphy, Marelich, & Hoffman, 2002). Hence this may result in mothers becoming overly sensitive to some of the things that may be signaling that the child is experiencing some difficulty in coping with maternal HIV-disclosure (Shaffer, Jones, Kotchick, Forehand, & The Family Health Project Research Group, 2001).

The mother's tendency to becoming overly sensitive may be particularly explained by the argument which posits that since HIV-positive women frequently present with depression, this may explain the mother's reasons for exacerbating their children's interpersonal as well as behavioural problems (Shaffer, Jones, Kotchick, Forehand, & The Family Health Project Research Group, 2001). Therefore it is plausible that this exacerbation may be as a result of the mother's apparent depressive symptoms and may be indicative less of the child's declining functioning (Shaffer, Jones, Kotchick, Forehand, & The Family Health Project Research Group, 2001). However this was found to be short-lived and decreased over time (Murphy, Marelich, & Hoffman, 2002). This view may in fact perpetuate non-disclosure of maternal HIV status as mothers may believe that it is the best option as their children deserve a life that is free from worries so that they may fully enjoy their childhood (Delaney, Serovich, & Lim, 2008).

Pertaining to the above mentioned reports by the mothers, it may also be that mother's lack awareness in regards to their children's internal moods which links to the argument that has been posited that children who have not been disclosed to are true in reporting high levels of negative self-esteem. It has been the case that children often suppress their feelings and can be quite protective of their mothers subsequent to disclosure. They do this as an attempt to not upset their mother so as to not add on to the stressors that she is already experiencing (Murphy, Marelich, & Hoffman, 2002).

2.2.2.1 Factors making it more likely for the mother to disclose and the implications thereof:

Despite maternal disclosure not being an easy process to engage with, there have been documented reasons that make it more likely for the mother to disclose about their HIV status to their children. Firstly, maternal income was specifically related to the mother's manner of describing the illness and their plea for children to be cognizant about the importance of keeping the illness a secret (Kirshenbaum, & Nevid, 2002). It has been the case that mother's

with a higher household income vs. mothers with a lower household income were seen to be more forthcoming with their HIV/AIDS status and being clear on it rather than being vague and not forthright with the name of the illness (Kirshenbaum, & Nevid, 2002). Secondly, mothers that have a history of abusing illicit substances were more forthcoming vs. mothers who did not have this kind of history (Kirshenbaum, & Nevid, 2002). Thirdly, mothers who had a psychiatric history were able to give a more elaborate account of their illness vs. other mothers (Kirshenbaum, & Nevid, 2002). Fourthly the longer the duration that mothers had known of their illness, the longer their children had been disclosed to. This can possibly be explained by the meaning and seriousness of being on a particular kind of medication. Being on antiretroviral medication has been seen to imply that children were possibly informed that their mothers may die from HIV/AIDS complications (Kirshenbaum, & Nevid, 2002). Lastly, the mother's disclosure of their T-cell count was mostly associated with a more detailed explanation regarding the disclosure (Kirshenbaum, & Nevid, 2002).

Depending on the depth to which disclosure takes place determines requests that mothers expect their children to carry out. For example, a more detailed disclosure would usually encompass the child being informed about their mother being HIV positive, followed by the often fatal experiences associated with the illness (Kirshenbaum, & Nevid, 2002). This inevitably creates opportunities for frequent questions and discussions regarding the mother's health status (Kirshenbaum, & Nevid, 2002). Thereafter having being informed the child is usually asked to keep the disclosure a secret (Kirshenbaum, & Nevid, 2002). However, it has been the case that children usually present with higher behavior problems when they comply with this request, that is, when this was assessed (Kirshenbaum, & Nevid, 2002).

In cases in which the mother's illness has advanced, it becomes a significant issue to address the reality of death and dying (Pilowsky, Sohler, & Susser, 2000). These discussions have taken place according to Pilowsky, Sohler, and Susser (2000), in contexts whereby the mother was no longer staying with her child/ children due to accusations of child neglect and use of illicit drugs. Thus the discussions often left the mother feeling shameful and guilty as they were not allowed to stay with their children (Pilowsky, Sohler, & Susser, 2000).

Other contributing factors that make maternal HIV-disclosure about the maternal HIV status an emotionally laden responsibility is partly due to other secondary disclosures that the

mother may feel are inevitable to conceal (Draimin, Hudis, Segura, & Shire, 2009). This includes the maternal figure acknowledging their history of substance abuse and the methods in which the illness has been transmitted. Research findings have always been supportive of planned rather than inadvertent or casual disclosure (Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy, Nguyen, & Schuster, 2010). The problem with the latter is that seemingly the adolescent does not fully accept the disclosure and therefore discussing matters such as anticipatory grief or negotiations that need to be made regarding custody arrangements seem to be undermined under such circumstances largely due to the denial of maternal HIV-disclosure (Draimin et al., 2009). Therefore preparations for the adolescent's emotional and social functioning end up not been taken into consideration. Even though planned maternal HIV-disclosure have resulted in much better outcomes, factors that have prevented mothers from actually following this route have largely been due to them worrying about their children's emotional reaction which subsequently increases their hesitation to disclosing (Jones, Foster, Zalot, Chester, & King, 2006; Rochat, Mkwanazi, & Bland, 2013).

Even though it has been argued that planned disclosure is preferable in the context of the mother-adolescent relationship, this in itself does not guarantee the absence of emotional instability following maternal HIV-disclosure. When considering such implications within the family context, it has been clear in a study conducted by Bauman, Camacho, Silver, Hudis, and Draimin (2002) that the more cohesive family members were with one another, the more distress and behavioural symptoms were noted in children. One possible explanation that has been postulated has been that the more cohesive the family is the greater the chances of the family members becoming enmeshed thus resulting in less effective coping strategies for children in times of loss and sadness (Bauman et al., 2002). This has been noted particularly in contexts in which the mother is particularly very ill.

2.2.2.2 The role of family members mediating the maternal disclosure process

Within an African context it has been depicted that a family is often not limited to a nuclear unit but extends to include relatives, close friends and even people from one's religious background of which all of these are considered extended family members (Mkwanazi, Rochat, Imrie, & Bland, 2012). It is within these spaces of interaction that any one's support system becomes enhanced as extended families have proven their ability to being able to broaden a person's social networks. Mkwanazi et al., (2012) have specified reasons as to why

they have deduced that extended family members may be a reliable source of support and comfort especially in a situation whereby one or more family members are living with a chronic disease. Postulated reasons include that within families there is a notable level of engagement which contributes to the emotional intensity and high level of intimacy felt. Furthermore due to their persistence over time and consistency, extended families have been understood to play a role that can provide an environment which can attend to the needs of children that have been disclosed to (Mkwanazi et al., 2012).

2.2.3 Poor socio-economic status and parentification

It has become evident that parentification is in most instances not a desirous option for most children/adolescents to assume even though they may be expected to. For instance, with the disproportioned allocation of services and resources in the country, it has been the case that poverty still affects most South African citizens. If there were accessible services available such as hospices or nurses even consistent mobile clinics to take care and assist mothers who are no longer able to fully do so for themselves, children/adolescents would at least to a certain extent be offloaded from the burden of having to assume responsibilities that are usually assumed by an adult (Campbell, Nair, Maimane, & Sibiya, 2008). It is a concern in the South African context when children/adolescents are exposed to such situations and at the same time find themselves with little choice other than to fill up the role/shoes of the parent who is no longer efficient to do so.

In response to economic crises adolescents and their families may seek financial assistance from immediate or extended family members, friends and neighbours. However, there remains an uncertainty pertaining to whether the aforementioned will be in a position to assist. Hence grass-roots organizations commonly funded by NGOs primarily assist with identifying and establishing a secure base for children and families that are in need of basic services and support. These organizations thereby strive to support, in general, destitute households that have orphans by providing for bare necessities. Furthermore psychological services, such as counseling, for example, are also provided and have been identified as imperative tools that can be used to strengthen the adolescents as well as their family's coping skills (Foster, & Williamson, 2000).

2.2.4 Stigma

Stigma is a concept that has been explained comprehensively by Goffman (1963). His explanation is useful for unpacking the manner in which stigma is understood and the responses that it elicits from people. Goffman (1963) distinguishes between three types of stigma types which include stigma of characteristics, physical stigma and stigma of group identity. Contextually, stigma of characteristics will be elaborated upon as it is the most relevant one for purposes of this study. This is primarily because this research is not focusing on stigma that is perpetuated by a person's race, nation or religion as it is the case in stigma of group identity. Furthermore neither is the focus on a person's physical deformities as explained by physical stigma (Goffaman, 1963).

Goffman (1963) has explained that stigma of characteristics implies "blemishes of individual characteristics perceived as weak will, domineering, or unnatural passions, treacherousness and rigid beliefs, and dishonesty." Therefore this implies that this type of category describes people in a very negative manner thus further contributing and adding on to felt feelings and experiences of shame. People that have been typically identified within this category have usually suffered from a mental disorder, have been imprisoned, have had some sort of an addiction, are homosexuals, unemployed or have attempted suicide.

Common responses of being stigmatised include trying to make amends to the part of oneself that is felt to being the major source of the infected person's to be stigmatised. This is often driven by the need to improve one's defects. However on the other hand, it has also been depicted that some people may use the fact that they are stigmatised as an excuse for explaining their own inadequacies in life (Goffman, 1963). Moreover, others assume a quite hostile stance and choose to rather criticize people whom they identify to be normal's. Others still, prefer hiding themselves from other people; however this has shown to have the effects of further isolating one and therefore becoming easily susceptible to depression and anxiety (Goffman, 1963).

Stigma against people infected with HIV/AIDS creates and intensifies barriers that ultimately ostracize/ discriminate infected people. For this research's context, it is important to also look at how affected people such as adolescents respond and cope through such adversities. It has been documented that the adolescent may actually find it difficult to access the emotional

support from family members as well as from the larger community (Draimin, Hudis, Segura, & Shire, 2009). Therefore as a means of protecting themselves from stigma as apparent from the community, adolescents sought hard to distance themselves from feelings such as sadness, anger, anxiety and hopelessness. In as much as children may try to conceal their feelings, evidence in a study conducted by Foster, and Williamson (2000) illustrates that parents were able to notice when their children became worried, sad, taking over responsibilities which they weren't used to and availing themselves more often than before (Foster, & Williamson, 2000). In these circumstances parents found it challenging to confront their children about this as they knew the source of their children's emotional backdrop (Foster, & Williamson, 2000).

It is an ongoing concern regarding the manner in which HIV/AIDS is being stigmatized in communities and the extent to which this is not only impacting on the infected person but also on the affected children as well. This is clearly demonstrated by the adolescents feeling of the need to reinforce their normal-ness in society. The felt need of viewing the self as normal and being or appearing to being the same with other normal children conceals some struggles/concerns that the adolescent might be experiencing. Perhaps by adolescents stating that they too are normal children it is a way of reassuring themselves against the uncertainties that come with experiences following maternal HIV-disclosure. The adolescents' reaction may be understood as a defence against feelings of vulnerability including also, ostracism due to stigmatization, the possibility of having to assume parental roles and/ the burden caused by the stressors associated with already having the experience of assuming such roles. Moreover children may also become isolated in their experiences as they feel particularly fearful of new situations (Murphy, 2008).

In an attempt to combat these feelings of loneliness and isolation, children have been moved from their homes/ parents and fostered by family members or relatives. This usually takes place in a context whereby the adolescent is unable to cope with maternal disclosure. Therefore within African cultural norms it has been postulated that children that are being fostered by family members or relatives need not be treated any different from children of the particular family or relative. This has been deemed important due to the need of protecting the children from discrimination (Gillespie, 2006). This is in keeping with the lack of resources that children usually suffer from as a result of not having support and enough

money to provide for their needs. Some of the things that children end up being exposed to because of their vulnerability include, violence, crime, teenage pregnancy, as well as HIV/AIDS (Gillespie, 2006). However, contrasting evidence has been apparent in a study of children affected by the chronic illness of parents living with cancer. The study stipulates that instead of the child relocating and moving in with other family members it is better for immediate family members (if available) to actually stay with their child or children at their home. This protects the affected child from experiencing fears of abandonment especially in cases whereby the parent/s is/are deceased (Helping children, 2012). This evidence can also be considered in this study as HIV/AIDS is a chronic illness thus making it more likely that the effect may be similar.

Adolescent's feeling of a sense of loneliness is not an isolated phenomenon affecting them only. That is their mothers too are prone to feeling the effects of stigma which may in the long run make it difficult for them to adhere to their treatment and may also negatively impact on their ability to take care of themselves and to support their children in the manner that would make it easier for them to cope with the disclosure. It has been illustrated in African settings that the construction of HIV/AIDS is closely linked to ideas about death and dying. It is these ideas that have significantly contributed towards mothers' fears pertaining to disclosing to their children (Madiba, 2013). The shortage of Anti-Retroviral Therapy (ART) in African contexts has deepened fears of being infected with the illness and having to disclose because the illness was regarded as a death sentence (Madiba, 2013). Taking this into consideration adults living with the illness have realized that there are certain aspects in their treatment regime that make their status to be conspicuous in the public realm. These aspects include attendance to a HIV clinic, adherence to ART and receiving a nutritional pack. There is an apparent paradox as these are the fundamental things that are needed for improving one's immune system and for maintaining a healthy life. Yet, these are the same things that make one an easy target for discrimination and stigma (Madiba, 2013). In an attempt to conceal these markers adults have been seen disclosing a wrong medical diagnosis to their children as they would prefer to say that they were suffering from tuberculosis instead of revealing that they are infected and living with HIV/AIDS (Madiba, 2013). Moreover adults went to an extent of scratching out the name of the medication from the ART bottles or they would try to take their medication in private (Madiba, 2013). Even though adults trying

to conceal the fact that they are living with an illness may only do so to a limited extent as their attendance to an HIV clinic acts as the biggest marker.

2.2.5 Changing maternal identity and the impact on the adolescent

Parentification following maternal HIV-disclosure within the family context has been a contested issue in terms of the manner in which the maternal role within the African situation is commonly understood (that is, the maternal role in relation to the expectations that one is to fulfill (Iwelumor, Zungu, & Airhinenbuwa, 2010). This implies that since mothers' roles are closely linked with being nurturers to their families and to the wider community, it seems that their compromised ability to fulfill this role results in their protective functioning being perceived as being less efficacious (Iwelumor, Zungu, & Airhinenbuwa, 2010). Some of the roles that mothers partake in are due to the role associated with motherhood which include, taking responsibility in rearing children which in most cases becomes the mother's sole duty as well as learning to bear with children (Sandelowski, & Barroso, 2003).

Some of the decisions that women have had to consider subsequent to being informed that they are living with the illness are encompassed by both moral and cultural decisions which include; disclosing one's status, considering the possibility of starting to make arrangements for the children's custody, deciding on reproduction and making the necessary arrangements for health care and social services. For pregnant women they may have to consider using antiretroviral drugs so that they protect their child from contracting the virus (Sandelowski, & Barroso, 2003).

Being a woman has been closely associated with embracing motherhood. Motherhood is understood to encapsulate roles that women carry out that sets them aside in a particularly unique manner which is respectable and often, is their source of pride (Sandelowski, & Barroso, 2003). Since HIV/AIDS is known to be highly stigmatised, then when a woman becomes infected with the illness, stigmatization intensifies because of the qualities expected of a woman in the context of motherhood (Sandelowski, & Barroso, 2003).
In Sandelowski, and Barroso's (2003) study women have been studied within the context of motherhood. It has been apparent from the study that motherhood presents paradoxical challenges which the mother has to make meaningful decisions and interpretations. It has been depicted that in most cases women found out about their HIV status at the same time

when they found out that they were pregnant (Sandelowski, & Barroso, 2003). Hence on the one hand pregnancy, which symbolizes the beginning of life, coincides with an illness which is associated with untimely death. Even though the latter may bring about sadness and disappointment however being informed about the former brings about hope in regards to determining whether the woman can be treated and continue living a healthy life (Sandelowski, & Barroso, 2003). Motherhood is viewed as a woman's ability to give life such as when they give birth which is a positive attribute however since motherhood also entails engaging with responsibilities that involve being a mother, this means that the mother has to decide to disclose at some point. The uncertainty of the disclosure remaining a secret as is preferred by most mothers is a phenomenon that is not easy to determine (Sandelowski, & Barroso, 2003). Moreover even though motherhood is highly regarded in society however within the context of HIV/AIDS it threatens to change perceptions of a woman and may ultimately weaken the mother-child relationship (Sandelowski, & Barroso, 2003). Within this context there is an assumption that the woman may have been involved in the use of drug, been involved in sexual work and also, the woman is perceived to place the "innocent" unborn child at risk of contracting the illness (Sandelowski, & Barroso, 2003).

When the illness has advanced to the extent that the mother is unable to partake in physical tasks, the mother's role and effect within the context of motherhood becomes diminished. Further examples of circumstances whereby motherhood may be understood to take on a disembodied practice includes; imprisonment as well as separation from one's children and death. It has been stated that motherhood is highly regarded due to the mother's fulfillment of embodied practices such as working for oneself and one's children so as to protect one's family for example from poverty (Sandelowski, & Barroso, 2003). Therefore the inability to fulfill the embodied practices has resulted in the notion of virtual motherhood which entails that the mother's presence may take a disembodied form yet still being transcendent. This notion elaborates just how women are willing to strive against being subjugated by the concept of motherhood within the context of HIV/AIDS. It is also the mother's way of expressing their devotion towards their children (Sandelowski, & Barroso, 2003).

It has been the case that due to the effects of stigma in society, mothers living with the illness will remain and be understood to be disembodied for as long as they are perceived to be having diseased bodies (Sandelowski, & Barroso, 2003). Expectantly the mother's response

has been noted to be guilt and possibly shame due to the realization of some expectations that may present a heavier load than was usually the case thus making it difficult for them to fulfill the roles that they have become accustomed to and the roles that defines their functional strata in society (Murphy, 2008). Therefore it has then become the case that other female family members such as the mother's sister or aunt take on the responsibility of assisting the family in ways in which the mother is currently unable to (Draimin et al., 2009).

2.3 Social challenges faced by adolescents

2.3.1 Gender Roles

Maternal HIV disclosure has been shown to impact differently on adolescent males and females. This is primarily due to the often different patterns of the mother's socialization in relation to both genders. That is, it has become apparent that mother-daughter dyads are mostly marked and distinguished from mother-son dyads because of the higher level of intimacy which has been noted to be the increased accounts of verbal interactions and the use of socio-emotional speech used in the relationship (Lichtwarck- Aschoff, Finkenauer, van de Vorst, & Engels, 2012). Therefore maternal HIV-disclosure itself may actually build on the former's relationship by enhancing trust. However it may be argued that this form of relationship may actually function to protect the female adolescent from experiencing depressive symptoms (Lichtwarck- Aschoff et al., 2012). For adolescent males on the other hand, a commonly held belief about traditional masculine gender roles seems to in many ways inhibit the opportunity for an intimate relationship with their mother (Lichtwarck-Aschoff, et al., 2012). Therefore this has then been understood to actually increase the male adolescent's risk for presenting with depressive symptoms. Related to this view is the reality that adolescent males are during a phase in their lives whereby peers play a central role in regards to the manner in which they understand themselves in the world (Steinberg, & Monahan, 2007). Hence this implies that the adolescent male experiences increased amount of pressure to conform to roles that are gender specific (Lichtwarck- Aschoff et al., 2012). This then suggests that adolescent females are more able to cope well in the midst of apparent adversities largely due to increased sources of support systems which enable them to problem solve more efficiently. In contrast, adolescent males have been depicted to struggle in such contexts due to their predominant use of avoidant coping strategies (Lichtwarck- Aschoff et al., 2012).

2.3.2 Peers and other significant relationships

The often unspoken need to keep maternal HIV-disclosure a family secret has become an assumption that some parents have assumed their children understand (Madiba, & Matlala, 2012). Inasmuch as secrecy has been embraced due to the seemingly protective role that it plays, it has been in most instances the case that the adolescent inevitably informs other people as well (Draimin et al., 2009). However, this often results in social rejection and discrimination that is perpetuated by relatives, neighbours or the community at large. It still remains that upholding a secret distances one from significant others as it isolates the adolescent from the social support that they need (Mkwanazi, Rochat, Imrie, & Bland, 2012). It is a concern as the need to uphold a family secret can ultimately lead to the children/adolescent becoming distant from their peers (for instance this is because it has been noted that due to suspicions about one's maternal change/deterioration in health that people are more likely to ask about such). However, the privacy and discomfort that encompasses conversations held about HIV/AIDS may be a reason explaining the negative attitude towards open discussions pertaining to HIV/AIDS. It has become apparent that mothers infected with HIV trust that their children would not disclose to other people and that they would not do this with the understanding of the nature and degree of confidentiality that should be maintained (Brackis-Cott, Mellins, & Block, 2003).

Due to not being fully trusting of especially the effects to which one could disclose to, for example a friend, about their mother's illness and to also be continually treated with unconditional support and care is something that is perceived to be a risky option to endeavor in (Draimin et al., 2009). This has been noted by nearly 50% of adolescents who showed a preference to name their relationship with fellow classmates and neighbours as only associates. It became evident that these particular adolescent's virtually had no emotionally close relationships with classmates and even neighbours. The only people really that they considered to be their 'best friend' were their siblings, relatives or cousins (Draimin et al., 2009).

It was understood that maternal HIV-disclosure would be a major social ramification as it was thought that it would make people to generalize the diagnosis to other family members (Vallerand, Hough, Pittiglio, & Marvicsin, 2005). However, it became evident that expectations and the stressors of mothers and the children's/adolescent's assumed "forced

secrecy" was certainly acknowledged. That is, the burden associated with having to keep up with such was expressed as with the explanation that some of the adolescents were understood to be walking around with 'acids in their bottles', which suggests that the children/adolescent's experienced overwhelming feelings that might explode if unprocessed well (thus leading to a buildup of negative emotions). In some instances children's responses regarding their mother's plea for confidentiality was respected and carried through primarily so that they could protect themselves against humiliating comments (Murphy, Roberts & Hoffman, 2002). That is, children assumed that they would be ostracized by their peers whom would think that they were also infected with the illness and may conclude that they have been infected via deviant behaviour (Murphy, Roberts, & Hoffman, 2002).

Contrary to the above cases there are instances whereby mothers are open to the suggestion of not coercing their children to keep the disclosure a secret. Some of the reasons that have been posited for this include; the mother's confidence regarding their children's decision pertaining to whether they want to disclose to others or not; when the mother is not ashamed about having the illness and is not ashamed and troubled about disclosing to others; when the mother believes that disclosure to others can actually educate and probably save a person's life (Murphy et al., 2002). Moreover mothers were open to the suggestion of allowing their children to disclose only to a selectively few people (Murphy et al., 2002). These people mainly included professionals such as physicians, therapists and teachers. However, close friends and certain family members were also included in the list of a group people who are trusted to keep the disclosure confidential. More importantly, mothers considered the disclosure safe to the above mentioned people because they felt that disclosing would not be mere gossip but could possibly help answer some questions or concerns that their child/ adolescent might need to address (Murphy et al., 2002).

2.3.3 Career and/ educational development

There are pertinent difficulties at school that most probably are being influenced by maternal HIV-disclosure about the maternal HIV status; examples including less impulse control meaning that ability to control emotions such as anger, irritation, sadness become inhibited to a certain extent (Vallerand, Hough, Pittiglio, & Marvicsin, 2005). Furthermore the adolescent's self-confidence may be detrimentally impacted upon which may then have led

some mother's to consider counseling services so as to address what seemed to be a display of disruptive behavior (Vallerand et al., 2005).

It has been argued by Foster and Williamson (2000) that a child's ability to focus and attend to their education may become significantly disrupted largely owing to the responsibilities which often accompany the parent's sickness. It has been depicted that it is most common that older girls are the ones who usually take over such responsibilities which include household and care-giving chores (Foster, and Williamson, 2000). An illustrative example of the seriousness of this phenomenon is clearly depicted in statistics that have been conducted in Uganda. That is, only 29% of orphaned children between the ages of 15-19 years were able to continue focusing on their studies uninterrupted whilst 25% lost school time and 4.5% dropped out of school (Vallerand et al., 2005). It was apparent from the study that children who still had a surviving parent or those who were fostered by grandparents had at least a 7% chance of continuing with their education (Foster, & Williamsom, 2000).

Due to the fact that as an epidemic illness, being affected by HIV carries with it other facets which are primarily determined by one's socio-economic status. This has meant that children have had to drop out of school and start seeking employment mainly because of money needed to pay medical expenses. Moreover since the medical expenses are important and may take priority, for sustaining a parent's health then the child's schooling might be put on hold depending on whether the family affords to pay expenses related to schooling or not (Foster, & Williamson, 2000).

2.3.4 Sexual vulnerability

Children experiencing poverty due to some of the effects of being affected by HIV/AIDS (as in the case of having a parent living with HIV) is seen in the increased sexual vulnerability that is often attracted by their living circumstances. For instance in cases whereby both adults have died and children struggle to access help and support from family members or organizations, they may end up turning to the streets as their last option for survival. However in these circumstances early onset of sexual activities, sexual abuse as well as commercial sex is prevalent therefore increasing children's vulnerability to HIV infection (Foster, & Williamson, 2000). This phenomenon was illustrated in Uganda whereby the sexual debut for orphans vs. non-orphans is way earlier for the former as it was documented

to be at the age of 12. The main reasons given for this included; economic need, peer pressure, lack of parental supervision, rape by strangers, relatives and teachers and discovery (Foster, & Williamson, 2000).

2.4 Summary

It is apparent that maternal HIV-disclosure is a process that should be taken seriously as it is a sensitive discussion for a mother to be having with her child or children. It seems that planned disclosure produces better outcomes in terms of how the children react and adjust to the new information. This is because unplanned and spontaneous disclosure has often resulted in quite difficult behavioural problems that children display which may subsequently interfere with their ability to do well at school and in other areas of their lives. However more work still needs to be done in relation to interventions that can assist South African women in planning the disclosure to their children so that less harm is done.

3. Chapter Three: Theoretical Chapter

3.1 Erikson's developmental theory on adolescents

Erikson's theory of psychosocial development will be critically analysed in an attempt to understand the adolescents more comprehensively. In Erikson's psychosocial theory of development there are eight stages of man that are highlighted. These stages begin from the trust vs. mistrust phase and end with the ego integrity vs. despair stage meaning that they are marked from infancy to adulthood (Erikson, 1950). It should be noted that the stages are understood to being progressive in nature that is, meaning that future challenges may be encountered if earlier stages were not successfully resolved. Of relevance for this research is the fifth stage, the identity vs. role confusion phase which will be thoroughly analysed and highlighted according to the research questions that have been raised. However the first four stages will be briefly introduced below.

3.1.1 Trust vs. basic mistrust

The trust vs. mistrust is a dynamic that becomes evident from birth and extends over the infant's first year in life (Elkind, 1974). The mother-child relationship depends on certain aspects which are essential for the child's development. The mother's consistent presence which is marked by continual care aimed at providing an environment which is comfortable

and safe for her infant. This entails that the mother engages with activities such as cuddling, fondling, playing and talking with the infant in an attempt to remove any conditions that may make the environment adverse or anxiety provoking (Elkind, 1974).

Overtime these experiences become a part of the child's inner world and contribute towards the child's development of trust (Erikson, 1950). As the child's inner experience of sameness and continuity strengthens and becomes more integrated, he/she becomes confident in their ability to trust themselves to regulate and cope with their urges (Erikson, 1950). There is scope for flexibility in the mother-child relationship as evident in that the mother gives the child an opportunity through her mothering skills to experience the world without being threatened or overwhelmed by it. At the same time the mother's involvement regulates the manner in which the relationship develops. A healthier relationship would entail the mother giving the child the space to trust within themselves yet knowing that their foundation of their trust is readily available should they need to be assisted. A sense of trust that develops within the child is further understood to be meaningful if grounded within cultural beliefs and values which ultimately form the basis of the child being comfortable with trusting themselves (Erikson, 1950).

It is apparent that maternal relationship is essential over and above the physical/ tangible aspects that can be provided to the child, for example, food. However in instances whereby this is jeopardized for example when there is a lack of the parent's continuity and sameness over time such as in cases when an infant is rejected, this may threaten the child's world and result in the formation of a mistrust dynamic. Erikson (1950) makes an example of how the parent's prohibitions and permission-giving strategies contribute to the sense of mistrust if this is not grounded in meaningful behaviour that is largely supported by societal beliefs and values. Even though the dynamic of trust/ mistrust is created early in the infant's development it does not mean that the mistrust dynamic cannot be overcome. Moreover this implies that under traumatic or severe stressful conditions the infant may have a mistrust dynamic activated (Elkind, 1974).

The relationship between the mother and their infant was acknowledged and considered with high regard as it was also apparent that the space between the mother and baby was inseparable (Long, 2009). In a study conducted by Long (2009) concerning the experiences of mothers living with HIV/AIDS in the context of motherhood being a contested issue especially when one is infected with the illness, it has been depicted that the mother's

interviewed took time in engaging and being present during their infant's development of their milestones. However the mother's presented with a tendency of being overprotective in terms of being highly attentive. The mother's behaviour was understood to be indicative of their need to portray their goodness and also, to protect themselves and their babies against possible infection and against the possibility of their own death (Long, 2009).

It has been depicted by a study conducted by Peterson et al., 2001, as cited in Long (2009) that there were no attachment differences noted between HIV positive mothers and HIV negative mothers. The only instance in which a different attachment was noted was when the mother had AIDS which signals that during such a period the mother's condition of her illness had become severe. This may be due to the inability of the ill parent to continue providing the emotional and social needs of the child which may be as a result of the child being moved to be taken care of by other family members or relatives (Media in Education Trust, 2002). This has been seen to be anxiety provoking and upsetting for the child who may tend to cry easily and be prone to become irritable (Media in Education Trust, 2002).

3.1.2 Autonomy vs. shame and doubt

The autonomy vs. shame and doubt is apparent in the child's second and third year of life (Elkind, 1974). During this phase it has been depicted that autonomy is thrived from acts which include, climbing, opening and closing, pushing and pulling as well as holding and letting go. During this phase it is important for the child to develop novel mental and motor abilities (Elkind, 1974). The ability to thrive through these activities is construed as accomplishments. Parents may reinforce this by permitting their child to experiment with these activities. However, it is only with the parents' approval that the child can better learn to control their muscles, impulses and their environment (no matter how insignificant this may be) which all contribute to the child's felt sense of autonomy (Elkind, 1974). When parents do not encourage their child to find their own way by doing things that he/ she is clearly capable of doing the child develops a sense of shame. Furthermore when parents do not regard "accidents" as norms such as when a child soils, wets or spills things, the child learns to doubt their ability in regards to controlling themselves in their environment.

It is crucial for the child to depart from this stage with a moderate, good enough amount of autonomy. However, when the child has too much autonomy there is a risk of the child having excessive control, which as Elkind (1974) has demonstrated, has the power and

potential of making the child's parents submit to their child's demands in a quite passive manner. On the other hand, insufficient autonomy felt by the child may make the child progress to other stages with a constant struggle to unleash their sense of autonomy as it has been arrested in the earlier stages (Elkind, 1974).

It has been depicted that in the context of children affected by HIV/AIDS that strong attachment patterns to their mother predicted high autonomy levels (Murphy, Greenwell, Resell, Brecht & Schuster, 2008). This implies that the healthier a relationship is between the child and mother the better and more functional the attachment pattern is. As one of the external behavioural problems suffered by children within this context has been a tendency to abuse substances in their adolescence phase Murphy et al., 2008). However this behaviour has been indicative of unhealthy development which results in less autonomous behaviour (Murphy et al., 2008). Furthermore it has been apparent that stronger attachment ties to one's mother and peers predicted higher autonomy levels (Murphy et al., 2008).

3.1.3 Initiative vs. guilt

This stage is evident amongst children when they are aged between four and five (Elkind, 1974). Children at this stage have good control over their bodies (muscles and reflexes) and are able to initiate their own motor play by themselves which may include running, skating and wrestling. Depending on the parents' willingness to permit the child to engage with these activities, only then will the child's initiative be reinforced (Elkind, 1974). This also includes that when parents take an interest to answering their children's questions that they reinforce within a child a sense of intellectual initiative. In contrast when parents discourage motor play or view it as an unnecessary activity, the child may then develop a sense of guilt over a phenomenon in which he takes initiative on which is then likely to be evident as the child progresses to other stages (Elkind, 1974).

It has been depicted that children affected by HIV/AIDS may worry a lot about the need to keep the maternal disclosure a secret. In obedience to their parents request for keeping the disclosure a secret the child may start making up false stories as they feel that perhaps their teachers or other people that they come into constant contact with will suspect that their mother is living with HIV (Mallmann, 2003). Hence the child starts living in a fantasy world so as to protect themselves from feelings of guilt should they 'mistakenly' disclose their

mother's HIV status to others. Also this fantasy world functions as a coping strategy. The unfortunate thing though is that children within this age group are not able to distinguish between reality and fantasy which may be argued that it impedes the child's ability to take initiative. This is because it has been proven that due to the effects of stigma associated with HIV/AIDS children affected by HIV/AIDS tend to withdraw from social contacts (Mallmann, 2003).

3.1.4 Industry vs. inferiority

This stage is apparent in children aged between six and eleven years (Elkind, 1974). During this stage the child develops the ability for deductive reasoning. This implies that the child can be able to understand rules of a game and also be able to understand other basic rules in life (Elkind, 1974). Moreover children show their ability to understand how things generally function in society. It is only when their parents encourage them and praise their efforts in, for example, taking part in building practical things that the child's sense of industry becomes enhanced. However in cases whereby parents see their child's efforts as meaningless or are not willing to encourage him/her, then a sense of inferiority develops (Elkind, 1974). This stage is marked particularly by the child's commencement at school. Therefore this implies that it is not only the child's home environment which builds their sense of industry as also the child's school teacher can take part in this as well (Elkind, 1974).

As the child within this stage is capable of deductive reasoning this entails that he/she is able to understand the role that stigma and discrimination play within the context of HIV/AIDS. Being aware of this the child's self-confidence is likely to be negatively impacted and this may be evident in their limited interest in establishing and maintaining friendships with others. This is apparent especially in cases whereby the child is actively involved in assisting with taking care of their mother's health (Media in Education Trust, 2002). This impeded ability to engage and take part in social activities lessens the child's ability to learn and improve their social skills (Media in Education Trust, 2002).

3.1.5 Identity vs. role confusion

As adolescents continue in their endeavour of integrating and strengthening their sense of continuity and sameness that has been taking place from earlier stages, the need to detach emotionally from their parents becomes of significance for a healthy ego identity to develop

(Erikson, & Steinberg, 2001). It has been argued that psychological perspectives uphold the view that it would seem rather adverse if the adolescent does not appreciate or feel the need to be their own person (Steinberg, 2001). This entails the adolescent consolidating their experiences in becoming more of themselves by taking into consideration experiences and aspirations that they wish to accomplish in future (Elkind, 1974).

The need to disengage from parents has been an on-going challenge with which it may be argued that the adolescent seeks to reconcile in this stage (Erikson, 1950). For instance this may entail the adolescent having a comprehensive understanding of oneself by integrating the different parts of the self in a meaningful manner. Moreover if prior phases in the adolescent's life have been fulfilled, that is, if the adolescent accomplished a sense of trust, autonomy, initiative and industry, then a more meaningful ego identity develops and has the potential to become enhanced over time (Elkind, 1974).

The response to the adolescent's need to disengage from their parents has resulted in different perspectives in terms of some aspects that parents and the adolescent tend to disagree with (Steinberg, 2001). For example this is noted in adolescents ability to start thinking about how other people perceive them. At this point adolescents may become aware that other people may think differently from how they think about themselves (Erikson, 1950). That is, parents tend to uphold a moral code which implies that doing things in a certain way makes it either right or wrong. This is, however, different for the adolescent who views and appreciates the freedom to exercise their personal choice (Steinberg, 2001). Taking the two differing perspectives held by parents and adolescents it has been apparent that the former may end up presenting with distress, thus negatively affecting their mental health as they perceive that all their efforts of educating their adolescents about the importance of respecting and maintaining basic values has not been strictly adhered to by the adolescent (Steinberg, 2001). Adolescents on the other hand may in many instances be less distressed about such if at all as they do not attach meanings to these kinds of conflicts (Steinberg, 2001). Therefore this implies that since parents have learnt the importance of upholding and being guided by moralistic codes then should the adolescent disobey these expected ways of living, their parents are more likely to worry whereas the adolescent may be less distressed as they continue taking their choices in life for granted. In the context of maternal HIV-disclosure it may be argued that since parents are more likely to become distressed when compared to their adolescent children that the same may apply when taking into consideration the effects

of stigma and discrimination. For example, it may be the case that mothers may engage in risky behaviours such as abusing substances which further negatively their health (Barroso & Sandelowski, 2004). Since adolescents are still at a phase in which they are learning more about who and what they aspire for in life, it means that if needs of prior phases have been successfully fulfilled, then this can play a protective factor against self-sabotaging acts upon being disclosed to (Barroso & Sandelowski, 2004).

It is when adolescents start to disengage from their parents in an attempt to becoming their own person that they allow themselves to consolidate roles and skills attained and those that they have been exposed to. This assists the adolescent to start thinking about important decisions for their lives, such as their careers (Meeus, Oosteswegel, & Vollebergh, 2002). However it is only when the crucial foundation of establishing trust as been laid that the adolescent can be better equipped in dealing with challenges encountered in subsequent stages later on in life (Erikson, 1950). Meeus, Oosteswegel, and Vollebergh (2002) have argued that the adolescent's decisions pertaining to school/ career commitment is a notion that is tied to their future and is significantly associated with the kind of relationship that parents have with their adolescent children. This is different from the kind of relationship the adolescent would have with peers which is mostly linked to the present and is associated with exploration and relational commitment (Meeus, Oosteswegel, & Vollebergh, 2002).

It was deemed that since the adolescent's world relies and is supported by relationships with parents and peers that it becomes important for parents to enhance their communicative relationship with their adolescent children (Meeus, Oosteswegel, & Vollebergh, 2002). In turn this implies that adolescents would be at a better place in terms of establishing good communicative relationships with their peers which makes it easier for them to explore more with school/ career opportunities. Meeus, Oosteswegel, and Vollebergh (2002) argue that the better the relationship adolescents have with their parents, the better the relationship is with their peers and ultimately the more confident the adolescent feels in relation to making decisions pertaining to their career.

However when the adolescent struggles to attain a sense of ego identity, such as when they struggle to consolidate prior experiences attained from earlier phases in a meaningful way, for instance in a manner that will assist in guiding their thoughts and decisions pertaining to their future, this results in a sense of role confusion. Furthermore this implies that there have been challenges along the adolescent's life that have hindered his/ her ability to attain a sense

of ego identity. Examples may include a difficult childhood or adverse social conditions. These challenges may inhibit the adolescent's ability in future to focus and to be confident on their career. Moreover it has been noted that adolescent's presenting with frequent symptoms of delinquency and promiscuous behaviour in adolescent girls has been as a result of role confusion (Elkind, 1974).

3.1.6 Intimacy vs. isolation

This particular stage has been known to depict in a person's life a period of courtship and early family life. This period is distinctly marked from late adolescence up until early middle age (Elkind, 1974). Intimacy within this context broadly extends from the narrow assumption which has been commonly associated with love-making. However it has been argued that intimacy importantly encompasses one's ability to share and take care of others without the fear of losing one's very own being. As with preceding phases it has been the case here as well that primary caregivers play an important role in terms of facilitating the success or failure for any one individual to be able to be intimate or not. If for any reasons the latter prevails, this means that the individual would be left in isolation having no one to share with or take care of (Elkind, 1974).

It has been depicted that within the context of maternal HIV-disclosure, adolescents may otherwise feel restricted to be intimate with people that they would under normal circumstances get support from. This has been commonly due to the controversies that often accompany an HIV positive status such as fear of death, stigma and discrimination (Qiao, Li, Zhao, Zhao, & Stanton, 2012). Furthermore it has been the case that within contexts whereby keeping the disclosure a secret is imperative, adolescents have been depicted to have weak intention to disclose to others, and they also depicted having a weak intention to telling the truth (Qiao, Li, Zhao, Zhao, & Stanton, 2012).. This in turn implies that the adolescent may deprive him or herself from accessing the emotional support which is commonly readily available in intimate relationships.

In sum, Erikson's theory has depicted that there are challenges in life and that it does not mean that when one finds solutions to challenges encountered in the different phases that similar kinds of challenges will not resurface again. Erikson's theory also highlighted that there is indeed hope in finding solutions to stages that one was unable to successfully resolve given the age constrains as explained by the developmental theory (Elkind, 1974).

3.2 Criticism to Erikson's work

Overall Erikson's theory of identity development has been questioned for the manner in which the phases have been set out and whether an adolescent does indeed progress in this postulated manner. This is still bearing in mind that the stage of identity vs. role diffusion includes a time in which the adolescent strives for personal definition and reorganization. However, it has been noted that some stages are experienced in a totally different sequence than the one set out by Erikson. For example, it has been evident in some instances that adolescents attain intimacy prior to resolving the identity phase (Lerner, & Spanier, 1980). For example within the South African context envisioning the progressive phases can be particularly problematic especially in situations whereby poverty is still an ongoing problem. Children are seen being forced by circumstances to engage in tasks that would be expected to be fulfilled by an adult. Therefore this implies that the postulated appropriate phases become compromised and contributes to the debate of whether this will contribute to a person's lack of contentment and overall wellbeing.

Furthermore it has been argued that due to the experiences and knowledge regarding the changes that adolescents encounter, it may be that some adolescents are eventually able to reconcile all the changes in their search for identity. However for others, it may be a very difficult process and Lerner, and Spanier (1980) have stated that the search for an identity has in some instances resulted in adolescents being 'lost'. Hence this has perpetuated the stereotypes often linked with adolescents that mainly communicate a message that adolescents have a maladjusted development. Moreover such stereotypes perpetuate self-fulfilling prophecies in the adult world pertaining to adolescent's fitting the stereotypical role.

3.3 Elkind's perspective on adolescence

3.3.1 Adolescent's egocentrism

One defining point of departure from childhood to adolescence is the latter's ability to start conceptualising and reasoning out ideas for themselves which provides the entry point for formal operational thought (Elkind, 1974). The defining feature of formal operational thought is egocentrism that characterises the experiences encountered by adolescence (Elkind, 1974). Even though this marks an unfolding developmental process it has been highlighted that egocentrism is perceived to be a negative phenomenon because adolescents tend to think and

believe others thoughts are always directed towards them (Elkind, 1974). When looking at Piaget's theory of intellectual growth, egocentrism is understood in similar ways in that it entails the lack of one's ability to distinguish the direction in which a subject's thinking is directed towards. Piaget refers this to the lack of differentiation of the "subject-object interaction" (Elkind, 1974; Jowkar, Rahimi, Zare, & Bafrooei, 2011). An illustrative example of adolescent's egocentrism includes being particularly concerned with the manner in which they appear to others and the manner in which others will perceive their behaviour (Elkind, 1974; Erikson, 1950).

There have been two consequences that have been highlighted concerning the adolescent's egocentrism and these include; having an imaginary audience and over differentiating one's feelings (Elkind, 1974). Adolescents tend to perceive in their world that what they think and feel about themselves is exactly how others think and feel about them as well. Therefore should the adolescent uphold certain negative thoughts and feelings about themselves, according to egocentrism, this is more likely to be perpetuated when the adolescent interacts with others (Elkind, 1974). A contributory factor is explained by the adolescent's apparent 'veil' which is the imaginary audience. This 'veils' the adolescent from seeing social situations in their realistic sense and not in how adolescent's imagine them to be. Moreover this 'veil' seems to create a rather uncomfortable feeling within the adolescent who seems to think that he/she is always the focus of attention. This is explained by the adolescent's increasing need for privacy and increased feelings of shame that result from the emerging self-consciousness that becomes apparent (Elkind, 1974). When taking Erikson's (1950) theory into consideration it is evident that shame is felt when one takes a critical stance towards one's beliefs or actions to an extent that the feeling almost becomes unbearable to tolerate.

Due to the inevitable process of egocentrism it may be argued that the adolescent may be vulnerable to risks because of the position that they assume to uphold within the imaginary audience perspective. The adolescent apparently believes to be a very important person possessing unique and special qualities that make him/ her outstanding from others (Elkind, 1974). Furthermore the adolescent believes that he / she is the only person that can actually experience, for example, pain or adverse circumstances with intensity which intensifies the belief that they are unique and on some level, interpret life's experiences very differently from adults (Elkind, 1974). However the more the adolescent believes this about themselves

the more they are vulnerable to exposing themselves to dangerous situations which can ultimately interrupt their future plans or even negatively impact on their health. For example, it has been the case that at times adolescents believe that they will not die and some females believe that they will not fall pregnant. This has resulted in adolescents practising unprotected sexual intercourse which increases their likelihood of contracting sexually transmitted diseases/ illnesses as well as falling pregnant (Elkind, 1974).

3.3.2 Adolescent's cognitive structure and experience

Since adolescence has been understood as a period in which the adolescent transitions into the adult life, this does not necessarily mean that the relationship with the adults becomes an easy one. Adolescents seek to differ from adults especially pertaining to decision-making processes (Elkind, 1974). The adolescent prefers rather to prioritise decisions undertaken by himself/ herself and their peers over those made by adults (Elkind, 1974). Even though the adolescent have this need, their indecisiveness still remains; meaning that inasmuch as they differ from their parents decisions they find themselves needing their peers support and more especially, their parents' guidance (Elkind, 1974). An explanation for the adolescent's apparent indecisiveness and the need to differ from their parent's decisions is due to their new capacity to conceive of ideal conditions. Even though these ideal conditions may seem appealing according to the adolescent's intellectual thinking, chances of the adolescent making this a reality are very minimal as they do not even have the understanding of what it is that may need to be sacrificed for such to be attained (Elkind, 1974). Furthermore adolescents may in the long run not even have the motivation and determination that will enable such ideal circumstances to come to pass (Elkind, 1974).

These cognitive structures that enable adolescents to have their own mind are less common in primitive cultures as there is no need as such for the development of advanced mental structures (Elkind, 1974). It is these mental structures that enable the adolescent to start considering other options that may at most times be different from the ones presented by their parents. Hence it becomes evident that adolescents experience more conflicts with their parents and rely more on their peers for making decisions (Elkind, 1974).

Within the advanced mental structure there is also another feature which the adolescent acquires; which is one's ability to think of oneself as an object. This entails taking an outsider perspective into one's own life in regards to evaluating one's personality, intelligence and

appearance. This makes it more likely that the adolescent becomes more aware and concerned with how others perceive him/ her (Elkind, 1974). Since adolescents seek to be approved and acknowledged by significant others, this raises questions regarding the consequences in cases whereby adolescents explore their world in an insecure manner which may be explained by the concept of 'shame' that has been raised in Erikson's second stage. That is it seems that the adolescent upholds a judgemental stance in how they introspect themselves in relation to other people. This is explained by the apparent secretive world that the adolescent creates which may be regarded as a safe place wherein they may keep their thoughts unknown from others thus reinforcing the idea that their thoughts are private (Elkind, 1974). This realisation enables the adolescent to speak out about things that are totally different from his/ her actual thoughts.

In sum, the capacity to introspect marks one of the entry points into adult life which constitutes of social disguises which can be conceived as defence mechanisms enabling the adolescent to cope better in regards to distinguishing what needs to be made public or kept private.

4. Chapter 4: Methodology

4.1 Introduction

This chapter encompasses a description of the research approach that has been used in this study. It includes the research paradigm, the participants, research context, the procedure, data collection process, consistency and credibility, self-reflexivity, ethical considerations and data analysis.

4.2 Research Paradigm

This study utilizes a qualitative method of enquiry grounded within interpretive phenomenological analysis (IPA). This approach is useful for understanding subsequent adolescent's behaviour following maternal-HIV disclosure within the South African context. The IPA method is derived from three theoretical approaches namely; phenomenology, hermeneutics and symbolic interactionism (Smith, 1996). The hermeneutics approach has been further looked into as it mainly and firstly focuses on enhancing understanding. It seeks to understand both the whole of a text as well as the parts that make up the whole of the text.

It has been deemed that the whole and the part of the text are in fact interdependent and have therefore been termed the hermeneutic circle (Smith, 1996). Secondly, it involves taking the location (context) of interpretation into consideration. This encompasses being aware and informed of the participants wider socio-cultural context which inevitably influences their responses to questions asked. Thirdly, this approach requires one to take into account the role of language and history which entails taking into consideration the manner in which language has been influenced and given meaning by history. Fourthly, the approach entails the ability to be alert and therefore to trace a common language between the texts so as to be able to extrapolate the differences and similarities or ambiguities noted between the different narratives of the participants. Lastly, this approach emphasizes the importance of being open to ambiguous narratives so that the researcher is in a better position to consider and appreciate the complexity apparent that may have impacted upon by the participant's history, language use and the uniquely situated nature (Smith, 1996).

4.3 Research Context

Research interviewees were recruited from a township close to Grahamstown, a city in the Eastern Cape Province of the Republic of South Africa. Grahamstown is also the seat of the Makana Municipality. The participants stay in Joza, a township in Cacadu district. It is about 111 kilometers south-south west of Eastern Cape's capital city of Bhisho and about 10 kilometres from Grahamstown.

It has been depicted that in Sub-Saharan Africa children and adults living with HIV/AIDS are 23.5 million (Regional statistics, 2011).

The following information is based upon the researcher's own observations. The long-standing challenges that have been experienced include; unemployment, high crime rates, poor infrastructure, domestic violence as well as substance abuse. To show that indeed these are serious matters that require well thought interventions, I was recently invited to give a talk about the dangers of abusing substances and also to inform the parents and youth at the Joza location about referral systems.

4.4 Participants

Since this study was developed using IPA, a small sample size was preferred consisting of four adolescents. This enables the researcher to be able to conduct a detailed understanding of

the participant's experiences (Smith, & Osborn, 2008). A homogenous and purposive sampling was used. This was due to the specificity of this study's focus which followed a certain criterion used to select the adolescents for participation. Of relevance, was that the adolescent had to have been disclosed to two years prior to taking part in the study and also they had to be within a certain age group. Moreover since the ability to generalize results was impractical, a non-probability sample was used.

During the interviewing process, the interviewee used a research schedule which served as a guide for asking questions.

4.4.1 Setting the scene: Who are the participants?

It should be noted that the participants are a particularly sensitive population as they are affected by HIV/AIDS which is an epidemic that carries with it a lot of shame and stigma mainly due to how people perceive those infected by the virus.

A total of four adolescents who have been disclosed to (that is, maternal HIV-disclosure) were interviewed which included three females and one male. However, only three female transcripts were used for data analysis. The male transcript was omitted on the basis that the interviewee struggled to engage with his emotions throughout the interviewing process to an extent that the data yielded was not enough for an IPA process as has been suggested by Smith, and Osborn (2008).

The participants' ages ranged between 18 and 20. The participants were recruited through an NGO known as the Raphael Centre. There are currently programmes running at the centre which are meant to support people infected and affected by HIV/AIDS. These include voluntary counselling and testing; education regarding the prevention of mother to child transmission; assists with access to treatment and caters for the needs of orphaned and vulnerable children by providing shelter and food (Raphael Centre, 2002).

Below is a brief description of the participants of the study. The participant's names have been omitted due to the necessity of respecting their anonymity.

Interviewee # 1

The first interviewee was an eighteen year old female who is currently living with her nineteen year old sister. She is in Grade 10 and is largely taken care of by her sister and her

mother is currently living in Cape Town. The interviewee was forthcoming as she spoke openly about her challenges, was very optimistic and held a confident attitude about her future.

Interviewee # 2

The second interviewee was an eighteen year old female who is currently staying with her grandmother, older sister and older female cousin. She is in Grade 11. Though she cried during the interview, she was forthcoming about her experiences.

Interviewee # 3

The third interviewee was a nineteen year old female who is currently living with her younger female sister (interviewee # 2). She is in Grade 12. She was talkative and quiet frank.

4.5 Procedure

The researcher (Ms. S. Sibanyoni) conducted all the interviews. Data collection took place over a period of two days, which was within two weeks (12th and 19th of April 2013) in Grahamstown. One interview was conducted on the 12th of April 2013, whilst the subsequent three interviews were conducted on the 19th of April 2013. All participants were interviewed during the week on a Friday, after school hours. Between the three interviews, an interval of ten to fifteen minutes was taken.

Interview sessions were all conducted on the premises of the Raphael Centre in the volunteer worker's office. This particular volunteer worker was actively involved in the recruitment process. The office had a table and chairs for the interviewee and interviewee.

The interviewer had to fetch the three female participants from their school on a Friday afternoon with the volunteer worker from Raphael Centre. This was because even though the volunteer worker stated and confirmed that participants were available, however, they could not get to the centre due to transport difficulties. For the male participant, I was invited by the volunteer worker to one of the cultural group activities that was taking place, meaning that the volunteer worker had already explained my study's aim to the participant. Therefore the participant was ready to be interviewed upon completion of the event.

Prior to commencing with the interviews, the purpose of the study was explained. At this stage it was explained that everything discussed during the interview would be kept confidential. The researcher also discussed the contents of the consent form (See Appendix H) with the interviewees. No language problems were encountered as participants reported that they fully understood what was written. The interviewer also asked the interviewees to express themselves in any language that they felt comfortable with. At this stage, the interviewer also requested the participant's permission to record the interviews.

4.5.1 Recruitment process and preparation

Ethical approval for the study was obtained from Management at an NGO, the Raphael Centre. (See Appendix F). Permission to conduct the interviews was also obtained from the above mentioned management. The first communication between the researcher and the centre was a face-to-face meeting in which the Management at the centre was asked to assist with the recruitment process. Thereafter the Management requested a proposal which was taken and handed in personally.

An Information Sheet for the organization was given. It consisted of the following information; the purpose of the study (which explored an adolescent's experiences following maternal HIV-disclosure and how this has affected them in the different areas of their lives); the researcher's contact details as well as her available times were provided (in case there were any questions or concerns regarding the research study); the inclusion criteria was provided as well as the study's description, interview procedure and information regarding privacy of information to be obtained. (See Appendix F).

Following this the researcher was given a tour around the centre which included being introduced to staff members as well as being explained to the different activities that take place and the respectable rooms allocated for such activities. It was noted that the centre promoted children's, adolescents' and adult's self-awareness, which were facilitated through means of art programs and more structured programmes such as counselling services.

It was after a period of two weeks subsequent to being introduced that the researcher was able to get hold of the participants for interviews. The three female participants were interviewed at the premises whilst the male participant was interviewed at a local primary school as he was taking part in a drama based activity that was facilitated by one of the staff members from the Raphael Centre.

4.6 Data Collection Process

It should be noted that a number of qualitative research methods, such as diaries, semi-structured interviews and personal accounts, were considered and can be used to gather data within an IPA method. This research study, however, used the semi-structured interview method. Semi-structured interviews were used to obtain rich data in order to explain participant's detailed accounts of their experiences following maternal HIV-disclosure (Smith, Flowers, & Larkin, 2009). Using semi-structured interviews provided an opportunity to get to know people closely and also, to gain insight into how they think and feel (Terreblanche, & Kelly, 1999). The semi-structured interviews "facilitates rapport/ empathy, allows a greater flexibility of coverage and allows the interview to go into novel areas, and it tends to produce richer data (Smith, Flowers, & Larkin, 2009). Moreover it has been noted that due to the flexible order of questions, the flow and manner in which views were shared became more natural (World health report, 2004). However, the shortfalls of using semi-structured interviews include the inability to replicate the study and often reliability has been cited as a concern as it becomes difficult to establish it (World health report, 2004). Also it has been a concern that the analysis is time consuming and that for significant meaningful data to be obtained the researcher should at least be informed about the participant's way of living and their cultural norms (World health report, 2004).

The interviews were recorded using an Olumpus VN-711PC audio recorder. The audio recorder was placed on the table top between the researcher and the interviewee so as to maximize the quality of the recording. The interviewer and interviewee sat opposite to each other. The tape recorder was switched on once the first question was asked and switched off at the end of the interview. The interview schedule was on the table so as to serve as a guide during the interview (See Appendix J). This option of audio recording was used since it made it easier for the researcher to handle the data as it stores much more information precisely and accurately. However audio recording has its shortfalls which include the fact that if unaware the sound may be flat and therefore may make it difficult for one to understand the audio when it is playing. Furthermore the audio recorder is easily damageable therefore meaning that if recorded information is not saved elsewhere then should anything happen to the audio recorder, all information will be lost.

The researcher transcribed the interviews verbatim. This option was chosen as it assisted the researcher to become more informed about the data. That is, it enabled the researcher to interpret non-verbal cues in a particularly meaningful manner.

The duration of each interview was approximately thirty minutes to an hour. Subsequent to the interviews, each tape was then labelled according to name, age, sex and grade, date and times of the interview.

Upon completion of the interviews, the interviewer met and sat with the volunteer worker to share the interviewer's experiences thus far. It was useful do to so as it helped to contextualize and better understand the response stance of the male participant. That is, this was interviewee # 1 who was close ended in his responses as he only highlighted the somewhat positive experiences, however, in a very vague manner. During this conversation, the volunteer worker was able to reveal that in fact, the participant was struggling at home as well as at school. That is, his behaviour was somewhat problematic at home and was also to an extent, uncooperative at school.

4.7 Data Analysis

The research method used in this study is called Interpretive Phenomenological Analysis (IPA). It is primarily concerned with the in-depth exploration of people's lived experiences. It explains a particular experience simply by elucidating what it was about the experience that held significance to the person. It also entails an interpretive process whereby there is a commitment to remaining as biographical as possible meaning that personal perspectives are thoroughly explored. Moreover it becomes central to actually highlight the meaning that a particular experience holds for an individual. This method has been chosen for this study precisely because it acknowledges that there is no simple way of understanding any one individual, hence it postulates that for a more enhanced understanding the biopsychosocial aspects of a person should be taken into consideration (Smith, & Osborn, 2008).

The following six steps outlined by Smith, Flower, and Larkin (2009) were used as a guideline for analysing data. Firstly, collected data from the participants was read thoroughly whilst simultaneously listening to the audio-recording. This was done so that the researcher could keep track of any contradictions and paradoxes noted (Smith et al., 2009). Secondly, the meaning of the participants' understanding of their experiences was highlighted and the

manner in which they expressed themselves served as a central guiding point into their meaning. Thirdly, the researcher interpreted emergent themes which included the participant's thoughts and original words.

Fourthly, themes that resonated and connected well with each others were organized via a superordinate theme (Smith et al., 2009). The fifth step entailed repeating steps one to four in a particularly sensitive manner that gave precedence to the idiosyncratic ways of understanding the data. Finally significant different as well as patterns that emerged were analysed (Smith et al., 2009).

4.8 Consistency and credibility

The interview schedule was constructed by the researcher and the supervisor. Information used to guide the interview schedule included relevant information based on the IPA questions and previous pertinent literature that has been conducted.

Consistency refers to the extent to which something can be considered to be trustworthy or dependable (Coleman, 2009). For purposes of this research study a similar approach of providing a thorough description of the research context was presented to all participants. Similarly the questions in the interview schedule were generally followed in a systematic manner. However this differed from participant to participant as in most cases participants elaborated on their responses which led to other areas of their lives being included in the data. This information was included as it was relevant for informing the richness of their experiences, even though their responses were not directly aligned with the questions. The procedure for coding data is under the section of data analysis which gives a systematic account of the manner in which the analytical procedure was followed.

Credibility refers to the extent to which something is considered to be adequate to the extent that it is deemed appropriate to satisfy certain standards or conditions (Coleman, 2009). This was determined by looking into the appropriateness of the questions being asked to participants. This was facilitated and guided by existing literature that has been conducted which has been deemed relevant for this study as well as from the supervisor's feedback.

Furthermore the study was guided by Guba's (1981) criterion on determining the trustworthiness of the study as has been briefly discussed under reliability. This entailed looking into the following concepts and implementing them into the study. These are

credibility; dependability; transferability; and confirmability. Reflexivity will also be discussed.

Firstly, credibility refers to the trustworthiness and believability of the findings (Bryman, 2012). In this study credibility was maintained by analyzing transcripts verbatim and semantically (Guba, 1981).

Secondly, in the criterion is dependability. Dependability refers to the ability to apply research findings and to determine whether these can be able to be replicated (Bryman, 2012). In the study dependability was ensured by means of using an identical format for interviewing each participant (Guba, 1981).

Transferability is the third process in the criterion. Transferability refers to the ability and extent to which research findings may be applicable in other contexts (Bryman, 2012). In this study transferability was ensured by means of providing a thorough description of the research context being presented (Guba, 1981).

Fourthly is confirmability. It refers to a process of determining whether the researcher's opinions have had a significant impact on the research findings (Bryman, 2012). In the study it was important for the researcher to acknowledge that their values and opinions were not neutral and to assess the extent to which this may influence data analysis.

Lastly, reflexivity refers to the researcher's responsibility in terms of looking into how their methods, values and decisions impact upon the meaning they uphold for their social world (Bryman, 2012). In this study reflexivity was ensured by writing notes in my diary which consisted of experiences throughout my engagement process with theory prior to data collection. Subsequent to data collection the researcher continued to keep note of how participants may have perceived the researcher's bias towards the research area (Guba, 1981).

From the above it may be argued that the research study employed methods that are both reliable and valid.

4.9 Ethical considerations

In order to commence with collecting data for the research study, ethical clearance and the permission to conduct the study was obtained from the Department of Psychology as well as the higher degrees committee.

Contact details of the researcher and the supervisor were given in case further containment was required as it is acknowledged that the participants are particularly a sensitive population and the research questions may be tapping into stressful areas in their lives, given that they are a vulnerable population. All participants agreed to and signed the informed consent sheet (refer to Appendix G). Participants were notified of the basic nature and procedure of the interviewing process. They were made aware of voluntary and confidential nature of the study as well as their right to privacy. They were informed of their right to withdraw at any given during the course of the interview and that should they feel uncomfortable answering a particular question that they are not compelled and obliged to answer it. Finally informed consent was given to participants only after they had given permission to tape record the interview (refer to Appendix I).

4.10 Self reflexivity

The researcher kept a diary which afforded her the opportunity to keep a record of her experiences prior to collecting data (during which a critical engagement with theory was being made). According to Guba (1981) this is an important process for the researcher to take part in. Notes of the researcher's personal meaning and feelings felt were being recorded. This continued during and subsequent to collecting data.

Personally I have always been keen on adolescents experiences affected and not infected by HIV/AIDS. Particularly I was more interested in how it was that adolescents managed to cope with the challenges encountered not only resulting from maternal disclosure but also from the new experiences encountered in adolescence. During the time I spent with the adolescents I experienced them as strong individuals who were particularly concerned about their future. Initially I was wondering where the adolescents source of coping and motivation came from but it soon became apparent that they motivated themselves despite the adverse circumstances that they were experiencing. I was particularly concerned as one's relation to their primary caregiver plays a very important role in the upbringing and well-being of any person. Hence with adolescents being affected by maternal HIV-disclosure I assumed that the disclosure and the implications thereof would take over their lives, leaving the adolescents to their own devices.

These assumptions were counteracted by research findings that actually proved that adolescents were able to be responsible and to take care of themselves and other members of

the family, if needs be. For an example it became evident that mothers infected with the illness were more likely to expose themselves to self-sabotaging behaviours like abusing alcohol and being emotionally abusive at times to their children. Under these circumstances adolescents became more cautious of experimenting with things that would sabotage their health and overall wellbeing. I realised from this that affected adolescents have resilience which strengthens them and gives them a positive outlook on life.

Overall there were minimal challenges encountered throughout the research process. The biggest challenge was accessing the participants and setting up a time that would be suitable for both the researcher and themselves. Furthermore the main obstacle was attaining participants that were just affected and not infected within the required age group. However I was able to work around these issues with the assistance of one of the volunteers at the Raphael Centre who helped with organising specific dates and ensuring that participants adhere to their promise to partake in the study.

The best part of the study was working with the data as it was unravelling. The intricacies and detail of the adolescent's experiences became much clearer. I come from a community that privileges the adults' opinions and values. Not that I dispute such but I believe that had this study not included adolescents, their voices would still remain shadowed by their caregivers perspective on the adolescents experiences. I think that the findings from this study have made me realise just how resilient adolescents can be even in adverse circumstances but importantly, I think adolescents have raised concerns regarding the need for supportive structures that are specifically tailored to meeting their needs. It is crucial that people in communities become aware of such so that effective support can be implemented before adolescents exhaust their coping resources in the context of being affected by maternal HIV-disclosure.

4.11 Conclusion

This chapter has discussed individual aspects of the methodology that have been used in the collection and in data analysis. This includes, the research paradigm, the participants, research context, the procedure, data collection process, reliability and validity, self-reflexivity, ethical considerations and data analysis.

5. Chapter 5: Results and Discussions

5.1 Introduction

The experiences of South African adolescents recounts the difficulties encountered following maternal HIV-disclosure, which impacts on the manner in which adolescent's make meaning of themselves and their world. It shapes their thoughts, decisions made and the manner they process their emotions. Even though maternal HIV-disclosure is likely to present with stressors, it has been depicted that certain ways of disclosing and also, one's support system are vital for a healthier and better coping strategies employed by the adolescent.

This chapter presents a discussion of the findings. However, it should be noted that it is the specific, unique experiences of South African adolescent's which are being explored, as has been stated by the study's aim.

5.2 Adolescent's and maternal relationships

5.2.1 Questioning the mother's love

Initially love between the infant and mother has been depicted to be centred on the infant's satisfaction of physiological needs such as the need to be fed (Bowlby, 1958). Moreover the infant's love for the mother becomes enhanced when other primary needs are taken care of (Bowlby, 1958). By taking into consideration Bowlby's experience it has been apparent that should the mother be accepting of the child's need to cling and follow them, then one may expect the infant's development to be favourable. This can occur even in the absence of breastfeeding. However it has been noted that emotional disturbances are prone to children whose parents refused them the opportunity to cling or follow them. The emotional disturbance persisted despite the fact that mother's may have breastfed the infant (Bowlby, 1958). Moreover this coincides with Melanie Klein's explanation which views the infant-maternal love to be mainly formed within the context of the infant's primary physical needs being met (Klein, Heimann, Isaacs, & Riviere, 1952 as cited in Bowlby, 1958).

A strong sense of being close to, of being supported and, above all, of feeling that one is loved during such difficult circumstances is something that the adolescent has expressed their need for. The adolescent's fears of not being responded to in such a manner may contribute to feelings of vulnerability and insecurity as depicted by the following quotes;

> *"I used to think that my mother was not able to love us enough due to the stressors that she was experiencing. However, I still do respect my mother and in addition to that, I absolutely love my mother. Even now that she is HIV +. I love her even more. I love my mother because she does not ever disappoint me, even when she does not have money to provide for something that I have asked for, she simply asks someone here in Grahamstown to help us out in the meantime. I love my mother dearly and totally respect her" (Interviewee # 1)*

It was evident that for participant one that the mere fact that her mother was still alive was reassuring for her despite the fact that her mother had decided to relocate from her home thus leaving her children to fend for themselves. The sporadic contact that she initiates with her mother continues to instil a sense of, hope within the participant in terms of being able to rely on her mother in times of need. Efforts made by her mother are felt to being a symbol of love and concern for her children. It is evident that it was not what her mother could actually provide that intensified her love but it was more of her mother's initiative and care for her that was of great significance. The same sentiments were shared by interviewee three;

> *The thing is, my mother's love for us never changed. She always used to maintain that things need not be different now that she is ill. At home, we still used to do things we enjoyed doing such as, hiring out transport to go to town as a family to buy groceries and other things we needed at home. (Interviewee # 3).*

Participant three's excitement was evident as she elaborated upon her experiences of still being able to feel the same kind of affection that she felt prior to her mother disclosing her illness. Even though the disclosure itself was not easy to process but for the mere fact that as a family they were able to continue engaging in activities together was important for the participant. Living with the illness and being affected by it may have brought about physical and psychological changes and challenges but that did not at any point distract the family's unity and love for each other.

However it was not in all cases that adolescents felt that their mothers cared for them. In most cases this is due to the latter's behaviour which then adds to the stressors experienced by the adolescent. Particularly alcohol abuse practised by the mother seemingly threatened and weakened the adolescent's experience of their mother's love.

Below is an extract that highlights some of the challenges that may impose on the adolescent's ability to feel love from her mother;

> *"The problem really lies with my mother. When she is intoxicated, she even insults us. When sober, she does not express her concerns face-to-face but when intoxicated, she has a tendency of bringing up all that is bothering her. She even insults us when we advise her and when we inform her about our concerns. We have to at least communicate to her our concerns when she is not intoxicated. However, we still run the risk of being insulted as there is a high possibility that she will insult us again when she is intoxicated (Interviewee # 2).*

Interviewee two was speaking within a context whereby her mother had relocated and had begun abusing alcohol. This meant that the participant felt that because of her mother's inability to provide for their basic needs, that her mother cared less for her. Moreover it was clear that the interviewee felt that her mother's use of alcohol jeopardised their relationship and may have made her to doubt her mother's love for her. The quality of their relationship took a different form as it became evident that the interviewee's experience of parental alcohol abuse as well as verbal abuse put her in a situation whereby she had to adjust her needs and concerns to those that would suit a time for when her mother was willing to listen to her. Despite this she never gave up on addressing matters that she felt needed to be heard by her mother. Being the oldest, she took the responsibility of being frank with her mother however she understood and knew constrains under which she could do this which however may have strained and negatively impacted on the adolescent's ability to receive love from her mother.

Interviewee two contrasts in the extract below, a time when she truly felt that her mother cared for them. This was prior to her mother being informed that she has been infected with an illness. The interviewee remembers the relationship in the following manner;

> *"It was alright because my mother used to pay attention and care for us. She worked for us; she loved and did everything for us. Even if we had done something wrong, my mother would not be upset for the whole day. She would speak to the person that had done wrong, meaning that she would never be angry at another person for a long time." (Interviewee # 2).*

The interviewee expressed herself in a lively manner and cheerful mood. Her mother's behaviour and manner of handling conflict reinforced a sense of peace and harmony in relation to her daughters. Being the youngest, interviewee one could not bear to witness her mother's sudden change of behaviour which seemed to reinforce the feeling that her mother did not care for her as much as she would have liked her to which seemingly made her feel distanced from her mother's care;

> *"The whole thing emerged when my grandmother was insulting her due to the fact that she was HIV+ and that she was also drinking alcohol. I think that it was alcohol that was driving her to actually be noisy and physically abusive at times. My mother's behaviour was really disruptive at times. This is because my mother would expect us to pay attention to her when she was shouting in the house. She did not take into account that she would usually do such things in the night and we would end up being sleep deprived and tired when we wake up the next morning." (Interviewee # 1).*

It is clear that concerns raised by interviewee one are similar to those highlighted by interviewee two which still carries with it anxiety felt around having a mother that abuses alcohol. It raised adolescent's anxieties as their mother's alcohol abuse threatened their basic needs being met which resulted in adolescents feeling that they are not loved enough. Upon consideration of the above quote interviewee one was elaborating upon her experiences which took place subsequent she had thought about committing suicide. This was in contrast to her initial account which depicted her mother in a good manner. The hardships that occur with having to process the disclosure became even more painful in a context whereby the mother has not processed that she is living with an illness herself. The sudden apparent anger outbursts displayed by the mother were an unpleasant experience and this was made worse as her grandmother was also unable to contain this anger in a manner that would not lead to further shame. Such acts may have made the interviewee to question her mother's loyalty and love for herself and older sister. It may be argued that living with HIV/AIDS requires one to emotionally process what it means to live with the illness and the impact that it currently has on one's life and the impact it will have on one's future. Hopefully this will minimise anger outbursts which in this case are usually directed towards already hurting adolescents who would understandably feel that their mother does not protect them from adverse feelings thus making her love questionable.

Adolescent's questioning of their mother's love may be due to the phenomenon that information regarding HIV/AIDS has been commonly closely associated with love and death. This is due to the leading manner in which the disease is transmitted and the drastic consequences that may befall one soon rather than later if the necessary precautions are not adhered to (Ostrom, Serovich, Lim, & Mason, 2006). It takes a unique relationship for one person to allow the next to take care of them as a lot of the times the one that is being taken care of exposes their vulnerability and dependent position. It becomes even more challenging when it is the adult that assumes this position rather than the child/ adolescent which seems to demystify the notion that it is more acceptable and perhaps expected for them rather than the adult to assume this position. However it has been apparent that the adolescent's found hope and strength to love their mother's even more. This is because their mothers were not afraid of acknowledging their difficulties and needs and in so doing reinforced their trust and confidence in them. Therefore according to Murphy (2008) this contributed to the adolescent's relationship with their mother significantly becoming enhanced in terms of both party's willingness to open up and to be accepting of support offered.

In cases whereby the mother had decided to relocate from their home, this was mainly driven by the painful effects of stigma that were felt in one's community (including family members). The adolescent's continual love for their mother despite the latter's personal decision may be an indication of how the mother may continue to be perceived in a good manner. This coincides with the understanding of virtual motherhood which supports the mother's position in a society that can be quite harsh and unsympathetic in these circumstances (Sandelowski, & Barroso, 2003). Therefore the mother's presence and love is not marked by their physical presence but more importantly, by the unique sentiments shared by both the child and mother in regards to their relationship (Sandelowski, & Barroso, 2003).

It is clear that interviewee's two determination in making a better life for herself and her sister defied the odds and challenges of confronting her mother with issues she felt needed to be discussed even when she was offended by her mother for doing so. This implies that the interviewee was capable of exercising her sense of initiative whilst risking the possibility of being shamed and ultimately, feeling guilty for being upfront with her mother.

5.2.2 Questioning perceptions held about the mother's identity

According to the identity theory it has been postulated that a person's identity is intrinsically linked to engaging in a specific role and evaluating one's behavioural outcomes (Burke, & Stets, 1998). It has been argued that the more clearly defined one's role identity is, the more it is expected that one's behavioural outcomes in terms of self-esteem will be enhanced (Burke, & Stets, 1998). Moreover a person's identity is encompassed by the positions that are assumed within social structures which are made meaningful by cultural norms and values. These positions form the basis from which a person's expectation regarding their own and other people's behaviour becomes apparent (Burke, & Stets, 1998).

Being diagnosed with a terminal illness and the meaning that one holds in such situations is important in terms of informing the extent to which it is felt that one's identity has in some ways, possibly being shifted, or completely changed. Interviewee three was particularly concerned regarding other people's perception towards her mother and if this would change;

> *"I also used to ask myself how my mother's disclosure would impact on her life, especially in regards to it being accepted in the family. Moreover, I was concerned as to how her in-laws were going to respond to this. Generally speaking, when you are HIV+, it is almost like you have been unfaithful. Your dignity as a mother is lost as people think that you are loose." (Interviewee # 3).*

Interviewee three's tone changed into one of seriousness as she related her concern. Her voice became soft and she continually shook her head as it became evident that feelings of distress overcame her. Thoughts and images of how her mother's in-laws would be relating to her mother seem to have been disturbing and dreaded. The participant continued to stare at the ground as she thought long and hard about this. After a while the interviewee' s demeanour took on a different form as she continued to narrated her story in a dismissive manner as she continually waved her hand in a disapproving manner. There was noticeable sadness as she could not perceive her own mother in such a derogatory manner. The participant was hurt by the negative labels attached to women that are living with the illness without having the necessary facts to support one's assumptions.

Furthermore there was a sense of overwhelming worry and distress caused by changes in the mother's behaviour which is something that can be very difficult to cope with (when considering other stressors that the adolescent's encounter). It became evident that with the

mother's often unhealthy change of behaviour, the adolescent became motivated to actually take care of themselves in the best way that they could. Interviewee one gave an account her mother's specific behaviour that was unsettling her;

> *"I worry about my mother. The last time she came to visit, it was clear that she had lost so much of weight…, meaning that she was abusing alcohol and not adhering to treatment. …since my mother has moved to Cape Town, the only thing that really worries me is in regards to whether my mother is taking her medication or not. She has informed us that the clinic is too far for her and therefore this tends to be problematic when she needs to collect her medication. By the way, my mother is very lucky when it comes to being employed but the problem is, she usually throws away the opportunity because she drinks alcohol. She really likes to drink alcohol." (Interviewee # 1).*

For this interviewee, thoughts of her mother suffering and experiencing such strain with little support (as her mother is living in another province), is very painful and unbearable to think of. The participant may be blaming herself for what she cannot do for her mother as a means of improving the latter's living conditions. The participant was also unsettled by her mother's seemingly sudden change of behaviour and this was noted by her fleeting eye movements which may have further been an indication of astonishment. The constant worrying may also be due to the interviewee's knowledge regarding the consequences of non-adherence to treatment and the role that substances may play in impacting negatively on an individual's health and overall functioning.

Another participant expressed her concern in the following manner,

> *"…I do not remember my mother drinking alcohol prior to being diagnosed with HIV. This has commenced probably due to stressors associated with being HIV +…or perhaps it is other stressors unknown to us. Since she moved to Cape Town, she drinks a lot. She does not consider the consequences. She immediately buys alcohol when she has money at hand" (Interviewee # 2).*

Interviewee two sobbed when she related her story. It was evident that she was troubled by the sudden change of behaviour that her mother was engaging in which she knew was jeopardizing her mother's health. There was also a sense of helplessness as the participant felt

that there was very little if anything that she could do to change the situation as she did not the exact cause of this behaviour.

Below, interviewee two was instead more concerned and worried about her name being associated with some of the things that her mother had begun doing in their community which was usually behaviour considered to be disapproved of by the interviewee.

> *"There are many things that have changed. My mother has been changing partners since she learnt of her status. She keeps on changing these men and this really bothers me. I keep on thinking about such things and end up becoming worried. I think to myself that my mother's behaviour is unacceptable. She cannot keep on changing partners in the manner that she is doing. As a person, one should have a stable, committed partner that one can be able to share, communicate and make life's decisions with. It is not good when she is changing partners the way she is doing because at the end of the day, we are the ones that end up being made fun of…hai…people make comments such as, 'it is X's mother that is engaging in such behaviour. People do not say, 'it is S engaging in such behaviour.' (Interviewee # 2).*

As interviewee two spoke she kept on taking deep sighs which was indicative of just how she perceives such comments to being inconsiderate and harsh due to their debilitating effects on her life. The participant's apathy is due to her inability to control the manner in which people think about such contexts, that is, children that are affected and not infected with HIV/AIDS. The inevitable association that people automatically make between parent's behaviour and their children's conduct is perceived in an unfair manner. Moreover it is clear that the interviewee has certain expectations pertaining to her mother's conduct which have been at this point disappointing and shameful.

Interviewee three below elaborates accounts that are similar to those of interviewee two;

> *"The thing is that people would just be so dismissive and they would often think that if one family member was infected, that other people in the family would also be infected. They would also think that everyone was a slut in the family. However, other friends of mine were very supportive and would disagree and dismiss what was said. Despite this, people used to discriminate against my family and I. (Interviewee #3).*

From this extract it is clear that the interviewee was aware of some of the verbal comments that were being made in her community. Even though the interviewee knew that these comments need not be true (as some of her friends also communicated this to her). However the reality and effect of hearing such comments seems to have impacted the interviewee to the extent that she may have also started to think negatively about herself and family. This is because encouraging words and support from friends was constantly being derided by harsh and inconsiderate comments.

In contrast, below, interviewee three chose to rather focus on the lessons that she could personally attribute and learn from to better her life circumstances instead of dwelling on the negative aspects only;

> *"…sometimes I think that perhaps my mother had different boyfriends or maybe that she had unprotected sexual intercourse with her boyfriend. So it is mistakes such as these that people have made in the past that I am cautious of. I believe that by not doing the mistakes that others have done in life will result in me prospering" (Interviewee # 3).*

Such comments downplayed the widespread notion that women play an integral role in society and are highly regarded within the respective domains of their families. Women are known of their strong will power, their nurturing abilities and steadfastness (Iwelumor, Zungu, & Airhinenbuwa, 2010). These are qualities that make women outstanding in society and highly appreciative in their respective families as well as in relations with their in-laws. It has been apparent that being diagnosed with HIV as a woman raises a lot of questions regarding ones fidelity as it became evident in the study that some women were not taking care of themselves due to their irresponsibility. This could be true but from the participant's perceptions, women were at the forefront of being judged and this escalated when they were not able to fulfil some roles that were specifically designated for them. It became apparent that by being infected with HIV and not being able to carry out these roles resulted in others depreciation of the woman's value in society and in families which signals the lack of respect that is often felt in the women themselves and their immediate family members (Sandelowski, & Barroso, 2003). Such stereotypes may contribute to the shame felt upon women's characters thus coinciding with Goffman's (1963) argument which states that the stigma of characteristics describes and attributes one with negative aspects. From the adolescent's experiences it does seem that the main coping strategy preferred and employed

by most mothers was to distant themselves from stigma and degradation from family members as well as from community members at large by abusing alcohol and at times, not adhering to treatment in the manner that they should be doing. In this context it is apparent that stigma and stereotypes have the effect of isolating women when they are encountering difficult circumstances which only exacerbate their anxiety and depression (Goffman, 1963).

Moreover it became apparent that adolescent's became more careful in regards to taking care of themselves despite the negative perceptions held in the community. This was apparent in the manner in which they conducted themselves in respective communities. This was contrary to behavioural problems that have been prominent with adolescent's from studies conducted by Jones, Foster, Zalot, Chester, and King (2007); Ormel, Oldehinkel, Ferdinand, Hartman, Winter, Veenstra, Vollebergh, Minderaa, Buitelaar, and Verhulst (2005). Moreover it was contrary to assumptions made that included the assumption that adolescents were more likely to experience behavioural problems as well as to have poor relationships with their mothers (Shaffer et al., 2001). Instead, the adolescents fought in maintaining a relationship with their mother as they continued to acknowledge the crucial role that their mother's played in their lives.

The manner in which women are considered to play an integral role in families, people tend to generalize children's behaviour according to their upbringing and qualities of life that have been instilled from a young age. Therefore this has resulted in suspicions regarding other members of the family, including children concerning their moral behaviour which is often brought into disrepute (Vallerand, Hough, Pittiglio, & Marvicsin, 2005).

It has been depicted that the biggest marker that makes one's illness visible to the public is attendance to an HIV clinic (Madiba, 2013). As an attempt to conceal all the markers that may expose one's vulnerabilities as HIV/AIDS is highly stigmatised and discriminated against, the mother's decision may have been based on her effort to protect herself from the unpleasant comments.

5.2.3 Fear concerning the mother's death

Fear of losing one's parent can be a distressing and scary thought to think about. The adolescents were expressing their experiences of how living with a chronic illness is a painful reminder of the possibility of a premature loss of a loved figure and at times, shattered hopes and dreams that fade away due to the loss of a loved one. Messages and images portrayed in

the media, stigma and the aura of fear surrounding messages concerning HIV/AIDS has created a certain meaning and understanding about what it means to be infected with HIV/AIDS. Even though there has been a lot that has been done to prolong the lives of infected people (for example medication, support groups, improved education on how one could better take care of themselves), there is still an irrevocable sense of impending death that is clearly illustrated below,

> *"…I do not know when something terrible might happen to a person because when you at least expected it, things can really go wrong. The thing is, if my mother passes away, things will definitely not be the same. Things will be much worse. I keep on hoping that at least my mother would be alive for the next coming two years so that she could teach me some basic skills that I need to learn so as to become self-efficient. Such things would make me consider that my mother has completed the work that God has sent her to fulfil." (Interviewee # 1).*

During this moment interviewee one covered her face with her hands in a particularly sorrowful manner. The possibility of her mother passing away and leaving them whilst they are still young was a terrifying thought. For this participant, life was altogether different prior to her mother knowing about her status. This was because her mother was able to provide for all her children. Her mother's attitude towards life drastically changed and this was depicted by her inconsistent attendance at work. Following this the interviewee had to be dependent on her older sister who is also a student but finds piece-jobs which serve as the basis of their income. It seems that even through their struggle, the participant finds hope and courage by the fact that their mother is still alive. Moreover the interviewee still feels the need of having her mother in her life as she feels that there are still some things she would like to continue learning from their interactions and relationship. This is despite her mother's inconsistent parenting and sudden disappointing behaviour change.

The same sentiments were also shared by interviewee two,

> *"…the only thing that bothered me was the thought of losing my mother at the age of 10. The last time she came to visit, it was clear that she had lost so much weight meaning that she was abusing alcohol and not adhering to treatment. When she was around, she used to ask me for money to buy cigarettes but I would not give her."(Interviewee # 2).*

Known facts pertaining to factors that contribute to one's ill health in the context of HIV/AIDS infection are similar to the ones stated by the interviewee. As the interviewee spoke, she shook her head in despair and in a disapproving manner. Below the interviewee describes concerns that she has pertaining to her mother that are in addition to concerns around death;

"My mother likes withstanding pain as she used to tell herself that she is strong. That is why we ended up forcing her to go to the hospital. However, she still did not want to go, I used to inform my aunt (mother's sister) as the latter used to listen to her…I was shocked!!! I just did not know what to say…to fill ashamed for her or…I just felt so confused. The other thing that was bothering me was the thoughts I had about my mother dying soon. I used to imagine that I would wake up and she would be gone in the morning. I used to think that she would not live long but she reassured me that she will."(Interviewee # 3).

Interviewee three further elaborated on a time when she had just been disclosed to. The disturbing images of seeing her mother's lifeless body was distressing her. Even though there has been an attempt to put aside the myth pertaining to HIV/AIDS being seen as a death sentence, however the overwhelming feelings felt by the interviewee seem to have evoked her fears and impeded her ability to think and consolidate the information in a rational manner. Furthermore it is apparent that the experience of overwhelming feelings was indeed anxiety provoking as she was unable to think clearly.

For participants who were particularly involved and committed towards maintaining their mother's well-being, the fear of losing one's mother could be closely tied to losing an integral part of oneself. Thoughts of how one would partake in everyday activities especially at home were an issue of concern. It was evident with the sense of gloom that overwhelmed interviewee three that having to lose one's mother was going to be experienced as intolerable change.

Such experiences may be denoted and perpetuated by children's immaturity in regards to not being able to demystify myths about HIV/AIDS which seem to have intensified their fear concerning their mother's death. Messages and images portrayed in the media of people living with HIV/AIDS have had an impact in how the adolescent's perceive and imagine that their mother's would be (Madiba, 2013). Contrary to evidence stipulating that HIV infection may be understandably perceived as a 'death sentence' in conditions where the necessary

treatment regime is not provided and is unavailable, in the study's context adolescents confirmed that their mothers were able to access treatment. It is known that when antiretroviral therapy is followed as has been prescribed chances of the infected person living a healthy and prolonged life are drastically increased (when other precautions are also taken into consideration and practiced) (Madiba, 2013). Despite this knowledge, adolescents fear surrounding the mother's death is real and imminent thus depicting the role that stigma has in terms of being a pervasive reminder of how HIV/AIDS is associated with ideas of death and dying in a society that is well informed and encouraged to eradicate myths surrounding the illness.

There is a sense of fear and doubt in one's capability to live life by themselves upon the death of their mother. This dynamic illustrates and confirms Elkind's (1974) argument concerning Erikson's theory which postulates that the successful integration in one's developmental stages does not assure that similar problems pertaining to a particular stage will not be encountered in future. In the study's context it is evident that participant's struggled with balancing and being confident with implementing their sense of autonomy which may be an expected response given their vulnerable situation.

5.2.4 Role reversal

It has been depicted that in cases whereby the mother requires their children to be their source of emotional support due to their inability of receiving this from other people, has resulted in profound consequences for the child involved (Kabat, 1996). Reasons that make this dynamic particularly concerning includes the lack of confidence that the child is likely to experience pertaining to setting their own life goals as their sense of self is more fragmentary than cohesive (Kabat, 1996). The child is also prone to experiencing difficulties in future regarding for example, establishing an intimate relationship with a partner. This is due to the child's difficulty in separating entirely from the mother and becoming their own self (Kabat, 1996).

In situations whereby the adolescent felt that the mother's illness had impacted on their lives to such an extent that the latter was unable to continue providing for them financially, it became a concern and ultimately a need for the adolescent to make means of providing for herself and younger sister.

"I decided to start plaiting on the side even though I am still schooling…if I am lucky I get one or two customers. From those two customers, I am able to make R100, as I usually charge R50 per person. However, I cannot keep the money as I quickly spend it by buying basic things that we lack at home. I buy immediately as soon as I get paid as I know the pressing needs that are needed at home. However by the time I get home from plaiting, I am already tired" (Interviewee # 2).

When interviewee two was relating her narrative her eyes were downcast and she was playing with her fingers throughout as if to communicate the message that as exhausting as it may be, she has no alternative but to continue trying so that she can meet both herself and her sister's needs. For this interviewee life has taught her to be responsible and to sacrifice the money that she earns so that she can be able to buy the necessities needed at home. The experience was draining for her but she still managed to stay focused on what needed to be done without being distracted/ losing focus.

Below, interviewee three illustrated that responsibilities are not only linked to practicalities that had to be taken care of, but also involved taking care of one's mother mentally, physically and emotionally as depicted by the following quote;

"Even when my mother became very ill in my grade ninth year, I was accustomed to taking care of her. I was accustomed to washing her by myself. This was when she became ill to the point of not being able to do anything for herself. She would just be lying flat on the bed. It was my sister and I who helped each other out as my father was at work… soon after my mother recovered it so happened that my father became very ill so my mother used to help us so that we could take care of my father. I also used to organize transport when my parents needed to go to hospital." (*Interviewee # 3).*

Memories were brought back of the difficulties that the participant and her family had experienced. As the participant spoke it was evident from how she tightly shut her eyes that she was recounting a troubling scene in her mind which mainly centred on the reality that assistance was not only needed by her mother but by both parents. This inevitably added to the burden felt of having to take care of the elderly. Feelings of deep pain were soon followed by those of disappointment as the manner in which she perceived her mother had started to take on a different view,

"I was never scared of things like having to wash my mother. I never doubted if I would be able to. I used to wake up very early in the morning, and then I would cook porridge for my mother and bathe her. I used to wake up at 5am and bathe myself first, then my mother. Afterwards, I would feed her (in the morning before going to school). I would then leave school break-time as it was not far from home to feed my mother during lunch time and then give her medication. I would then go back to school once I was done. Upon returning from school, I would feed my mother her supper. I would then also give her medication at around 7pm, and then bathe her again. Subsequent to this, she slept. I also used to make it a point that she did not strain herself by engaging with demanding/ heavy tasks as she was a person that liked to keep herself busy at home. So I used to clean the house and I would also wash her laundry, however sometimes my aunt would offer to wash it herself. Sometimes, my sister would offer to wash it when she was off from work." (Interviewee # 3).

Here the interviewee was reminded of the crucial tasks that she had to fulfil on most days. As she further elaborated on the tasks that she had to engage with the participant's face lifted and she smiled briefly. The difference that the participant made each day to her mother's life was something that could bring joy in her life. Therefore this illustrates the participant's resilience in that, even during adverse circumstances the participant was still able to appreciate the good things that she had imparted to her mother's life. The participant's dedication and extraordinary care for her mother seemingly saw her through these responsibilities.

However at times one does not get the support needed from family members during these difficult times (as was the case with interviewee three) as is depicted by the following quote;

"Things will certainly be difficult for me and my sister. I do not really get along well with my family members (from extended family) because they always pass remarks such as that I think highly of myself. That is because I do not ask for things we need at other people's homes. I only ask from my maternal grandmother's place. The misunderstanding between us has been on their faulty expectation regarding being plaited for free. They require this whilst still being fully informed about the situation at home. I would rather plait someone else who is going to pay me for my services. My family always say that I only think and work for myself and my sister" (Interviewee # 3).

When interviewee three was recounting her story she was moving about her shoulders almost as if they had been strained. It is evident that extended family members' inability to provide their support to adolescent's affected by HIV/AIDS exacerbates the burdens felt and intensifies the struggles that the adolescent has to encounter from a tender age.

The role that may be assumed by the adolescent in regards to taking care of their mother when the latter is fully unable to do so may be the adolescent's manner of conveying their care. There are different ways in which adolescents may show their care but it is apparent that the severity and effects on the mother's health determined the level of care needed. This implies that the more intense the severity and care needed, the more the adolescent may be needed to take part in assisting their mother and possibly, other family members in performing physical practicalities. Furthermore this means that the form of care needed may go over and above exchanging words of encouragement. It became evident that the kind of care required the adolescent's involvement and commitment that is driven towards maintaining good health for their mother. Instead of being a natural response from the onset as suggested by Delaney, Serovich, and Lim (2008) it became evident that the adolescent's care improved as they became more accepting of maternal HIV-disclosure and learned ways of being unconditional present when needed. Furthermore in regards to being treated differently by other family members, the effects of stigma may further reinforce adolescent's perceptions of themselves being treated different from other adolescent's that are not affected by HIV/AIDS as has been evident in the manner in which they are ostracized by other family members (Murphy, 2008).

5. 3 Adolescent's relations with peers and significant others

5.3.1 A lost part of self

Adolescent's relations with peers play a crucial role in terms of enabling the adolescent an opportunity to enhance their development and socialization skills which is an intrinsic process in their transition to adulthood (Slaughter, & Griffiths, 2007). Forming friendships does not entail a random set of events that take place. It has been argued that there are two processes that are usually scrutinised prior to the initiation of a friendship taking place. In particular this process includes selection and socialization (Slaughter, & Griffiths, 2007). The selection process entails the meeting of two people who find in each other common interests that forms the basis for their mutual attraction towards each other (Slaughter, & Griffiths,

2007). These interests encompass personality traits, physical characteristics, values and behaviour. Secondly, the socialization process stipulates that the relationship existing between a pair of friends intensifies and becomes enriched due to their commitment in being together thus further enhancing their mutual interaction towards each other (Slaughter, & Griffiths, 2007).

For interviewee three below it is clear that her ability to engage with the selection and socialisation process were compromised mainly due to the responsibilities she assumed at her home;

> *"Personally, I never really had time for friends. The only person that I spend time with was my mother. I just got used to the routine of spending my time with my mother when I came back from school and when she came back from work. I would sit and do my homework's which she would usually help me with, and then I would sleep afterwards. I think it became easy for me in that manner because I was so accustomed to being with my mother and I did not feel the need to go out to be with my friends." (Interviewee #3)*

The interviewee was elaborating on how her life had become focused on her mother's life and to a lesser extent on her school work. She did not find time to do things that other adolescent's would usually do due to her responsibilities at home. It became evident that the above mentioned circumstances constrained the interviewee's choice of acting out of free will such as choosing to spend her free time with friends. The interviewee continued to elaborate her experiences soon after her mother had passed away;

> *"…my mother's death was so recent so I used to ruminate about how life would be since my mother was no longer alive. Concerns regarding what I would be doing in my spare time bothered me the most as I was accustomed to sitting and chatting with my mother from school. However, since my mother's death I would come back from school and sleep. I did not study or do anything really, I would just sleep." (Interviewee # 3).*

There was an apparent sense of hopelessness in the interviewee's experiences as she remembered days when she felt that life was meaningless. The sense of gloom which was expectantly accompanied by the mourning phase seemed to have been intensified in the interviewee's case as she dedicated and spent most of her time caring for her mother. It was

also apparent that the effects of having to process the sudden loss of a loved figure was exhausting for the interviewee who struggled to come to terms with creating new meaning for her life and starting afresh on a different path that did not entail her assuming the role of a carer. However as time progressed the interviewee was able to start focusing on herself and her own needs. The following extract makes this explicit;

> *"I like resting from school, then going to the gym at 4pm. Thereafter, I come back home to complete my homework's and then sleep again. I do not engage in hard/strenuous work at home. Regarding friends, I only see them sometimes during weekends only when we play rugby. My mother used to support me when it came to my sporting interests. I actually started playing last year and I was even chosen to play for the Eastern Province. So my mother used to encourage me to play sports rather than to go out to taverns to drink alcohol and spoil my life." (Interviewee # 3).*

Inasmuch as the interviewee was willing to assist her mother in the best way possible it seems though that she became over-involved to the point that she could not be her own person as she was too attached to fulfilling her mother's needs. She spoke in a relieved manner as these were exciting new endeavours that she had created for herself. Furthermore her mother was aware that her daughter needed to have and experience a life that was separate from hers. It may have been that the interviewee's insistent sacrifices were more to do with how she felt and less with the actual demands made by the mother. Perhaps the decision to be involved in taking care of her mother was the participant's way of exercising her free will which may have buffered against feelings of guilt and inadequacy during a time when her mother was in need of her family's care.

Notwithstanding the challenges experienced when living with a parent that has a chronic illness is something that is indeed difficult for any child but the challenges encountered do not preclude a life that is normal and enjoyable. This is because the parent's illness does not in itself define and determine the course of the adolescent's development as it is only a part of the adolescent's life and does not take over the child's existence (Helping children, 2012). However due to the adolescent's egocentricity they may feel that they are responsible and somehow are to be blamed for the illness that their parent is presenting with. In such situations, adolescents may become more controlling and less dependent in terms of needing assurance from their parent/s (Helping children, 2012). This kind of behaviour was apparent with interviewee three's explanation of her behaviour as she chose to be over-involved with

assisting her mother despite the fact that she had an older sister and aunt who were willing to assist her. This may have been primarily driven by her attempts to conceal her feelings of sadness, anger and fear from her mother as she could have thought that if she were to disclose these feelings they would worsen her mother's condition as the latter would worry more. Therefore the parent's awareness in the complexity of their child's thought process may be of assistance in regards to making this an open discussion and normalising feelings that are thought of by the adolescent to be unacceptable and shameful to share (Helping children, 2012).

The tendency to assume a controlling stance (that is, to take over most responsibilities) in this context may signify the adolescent's feelings of inadequacy and lack of control over their environment and the events taking place (Erikson, 1950). Therefore parents have been encouraged to communicate to their children that their illness does not imply an impaired development. It is the parent's responsibility to motivate and encourage their children to take part in other leisurely activities such as sports so that they can learn to have a life of their own (Helping children, 2012). It has been stated that when parents encourage their children to pursue other activities that make them happy, they are communicating the importance of self-care and of maintaining balance in one's life for the development of a healthy self such as is the case with interviewee three's mother (Helping children, 2012).

5.3.2 Feeling different from peers

It was evident that the adolescent's experiences thus far and at times, the socioeconomic situation at home, played a role in setting one apart from other peers who were not experiencing the same kinds of challenges. Interviewee two elaborated clearly on this phenomenon;

> *"...I feel that I am different. Sometimes I feel like they do not really care about me and my situation. Sometimes one of my friends would be telling us about petty conversations she has had with her mother; or would even talk about things that they have been bought for by their parents whilst on the hand I am bothered about more serious concerns. These include things that my siblings and I need at home. So sometimes I just prefer staying at home with my sister." (Interviewee # 2).*

As interviewee two explained her reasons for feeling different she kept rolling her eyes in a childlike and teasing manner but towards the latter part end her tone became serious as she

was reminded of her reality and the hardships she experiences. Furthermore the interviewee's narrative illustrates the extent to which she feels unheard and misunderstood by her peers. This was evident as she would at times shake her head in a disapproving manner. Also, it almost feels that the interviewee felt alone in her experiences as her peers were not playing the supportive role that she needed in her life.

Interviewee two continued to illustrate just how priorities have become markedly different when compared to herself and her peers as denoted below;

> *"…Even though I do share with them my experiences but I still find some of my friends speaking in my presence about the good things that their parents have bought them during the end of the month. They speak about these things not considering for instance that at my home, there is no meat and also, that I simply cannot afford to buy something's that we need as my mother does not send us enough money…hence the reason why I prefer staying at home is because my friends do not even think about sharing something's with me and my sister." (Interviewee # 2).*

Interviewee two was referring to some of the things that the adolescents are being bought for by their parents such as food and clothing which is something that her sister and herself struggle to attain. The interviewee's volume became loud and somewhat irritable and this may denote the frustration felt in regards to not being able to live a life similar to that of her peers which seemed to be so good. There was also underlying emotions of sadness as the participant's hopes of living a better life and her current reality were different.

Similarly below interviewee two's expression of her need to try and partake in activities with her friends but her social situation made this impossible for her;

> *"The only thing they want to do is to have fun by drinking alcohol and smoking. I cannot partake in such activities because even when I have money, I constantly think about the things I have to fulfil at home. My friends just do not want to hear about such things. When they have money, all they think about is fun. I just cannot do that with them. I just do not have time for fun as I have responsibilities that need to be taken care of at home. I would rather accept that they do not like that part of me then." (Interviewee # 2).*

During her explanation the interviewee was noticeably in deep thought mainly about the things that she has had to give up in order to stay focused on providing for herself and her sister at home. The interviewee's sudden stillness and brief silence was noted as she sat and continued thinking. This may have been an indication of the interviewee's preoccupation with the responsibilities that have bounded her to sacrifice most of her time and self for a better living.

Even in her stillness there were apparent feelings of frustration mainly due to not being heard and understood in the manner that one would like to be. In contrast, interviewee three provides an account that made it better for to accept her situation and to fight against feeling frustrated in a particularly meaningful manner;

> *"…I learnt not to compare myself with children whose parents were able to afford certain things that my parents could not afford. An example to illustrate this point is that I only started having a cell phone now in Grade ten. My mother used to tell me that it was not important as she needed to prioritise things that I needed for school and not on something that would be spoilt within a short period of time." (Interviewee # 3).*

The interviewee's mother played an important role in regards to making it clear about their circumstances at home and the realistic limitations that they were presented with. This seems to have been taken well by the interviewee who understands her socio-economic background and is willing to live a life that is within her parent's means thus circumventing any feelings of frustration that may be felt when evaluating other adolescent's life whose parents are better off financially.

This ability illustrates the adolescent's ability to think outside of themselves and to evaluate their circumstances. Furthermore this illustrates how the adolescent learns to judge their circumstances on a comparison basis to those of other adolescent's, especially their peers. This cognitive ability enables the adolescent to start teasing out aspects that make them who they are and thus, different from others (Elkind, 1974). The basis from which the affected adolescent makes these comparisons has been mainly due to the difficulties that they often encounter in regards to attaining basic needs such as food and clothing. These difficulties also often compromised the adolescent's ability to be fully present at school. Hence it became

evident that the adolescent's experiences at home were not isolated as they often determined their functioning in other areas of their lives.

Contrary to work conducted by Mkwanazi, Rochat, Imrie, and Bland (2012) which argued for the importance of keeping maternal HIV-disclosure a secret among only certain family members, it has been depicted that the matter became a public rather than a private issue. This is because disclosure took place in a context whereby the mother's aim was aligned more with educating their children and less with addressing the need for disclosure to remain a private issue.

Taking the disclosure and subsequent conversations related to the topic, it was evident that adolescent's awareness became heightened more importantly from their experiences and daily interactions with a loved one who was infected with the illness. However the consequences of not keeping the disclosure a secret was felt in quite a harsh manner by the adolescents who felt that they were not only treated differently because their mother was HIV infected but were also felt unfairly judged for their mother's apparent frowned upon behaviour. This included behaviour from their mothers such as abusing alcohol as has been mentioned. Therefore it is evident that being infected and directly affected by HIV/AIDS such as the adolescents may intensify criticism held towards infected/ affected persons. For example, one participant noted this phenomenon by postulating that people in the community as well as peers are more likely to pass critical and derogatory comments to a person infected with HIV/AIDS despite the fact that the infected person continues being responsible in terms of fulfilling her responsibilities when compared to a person who abuses substances and does not take care of family.

5.3.3 Rejection by peers

It has been postulated that sensitivity of being further rejected heightens when one has been rejected by peers and this has been correlated with common anxious and angry presentations in one that has been rejected (McLachan, Zimmer-Gembeck, & McGregor, 2010). Parental acceptance as well as forming new satisfying friendships provides hope for one to overcome the adverse effects of being rejected. However more prominence has been given to parental acceptance as it has been deemed that parents may be able to communicate the message through their guidance and assistance that peer rejection does not fundamentally entail an

internal way of being neither does it proclaim a certain stable pattern of relations (McLachan et al., 2010).

Depending on the level of understanding and willingness to support the adolescent affected by HIV/AIDS this contributed to whether the adolescent would be rejected or still be welcomed by his/ her peers.

> *"They would vehemently state that they would not share things with me. Even when sometimes I needed assistance with my homework, they would refuse to help me by stating that they are not teachers and therefore I should ask the teacher. I just ended up keeping quiet if I was struggling with my school work. I even ended up not doing it. I also kept quiet about this to the extent that I ended up not informing my mother about my challenges." (Interviewee # 3).*

Interviewee three related her narrative in her bashful manner as she looked down and played with her fingers. At times she would giggle in a nervous manner. This may be due to the fact that her experiences of how other pupils treated her were unpleasant and discriminatory. The adolescent further explained that following such hurtful and insensitive comments she began having suicidal thoughts. However she explained that her mother had already spoken to her about the consequences of committing suicide to the extent that she understood that her life was important and that she need not take it away. It was just in moments when she felt alone in her difficulties that the interviewee thought of committing suicide.

Below, interviewee three provides an account of how it is that she experienced her peers from the time they knew about her situation. Moreover she began feeling bad for something that she was not even sure about.

> *"…especially at school after I disclosed to my friends. Some of them would not even want to be close to me and would not even want to share food with me when I offered. I would feel guilty as if I have offended my friends in some way, unknowingly to me though. When I enquired they would just reply that there was nothing. I also used to ask myself if my friends would desert me on the grounds of thinking that I am also HIV positive. (Interviewee # 3).*

Interviewee three's face was filled with contempt and disgust as she related her story. It is apparent that the interviewee may have begun to take on some of the negative attributes that

were being spoken of by her peers. That is, she may have began to feel that she was not as good or likeable as when compared to her peers because she had a mother that was infected with the illness. The following extracts demonstrate the extent to which interviewee three had begun to act in ways that unintentionally confirmed that she had a reason to self-loath or to look down upon themselves. As interviewee three spoke she became tearful as she recounted just how these comments had the power of negatively impacting on her self-esteem and the subsequent effects of feeling lonely and being ostracised from her circle of friends became real.

From the extract below it is apparent that it was not all interviewee's who were excluded from other pupils;

> *"I usually start doing my school work late in the evening once I am done plaiting people's hair. I always try to complete work that I could not finish at home, early in the morning at school with other pupils helping out." (Interviewee # 2).*

Interviewee two spoke with ease and in a relaxed manner as she communicated her confidence in trusting other learners' to supporting her when she needs their assistance with school work. Feeling supported, interviewee two was able to manage and not give up on her studies or feel defeated in her struggles. The support was very important in terms of strengthening her belief that she was able to do well and in reinforcing the idea that there were people who recognized and acknowledged her difficulties.

The support system plays an important role in terms of buffering against negative perceptions commonly held by people in the community in relation to people infected with HIV/AIDS is perpetuated by stigma which is at most discriminatory and carries false claims (Goffamn, 1963). It has become apparent that the adolescent, even though not infected with the illness the adolescent becomes susceptible to feelings of guilt and worthlessness. Elkind's (1974) theory of the adolescent's egocentrism explains reasons pertaining to the adolescent's manner of taking on widely spread negative perceptions onto oneself and acting these out. This entails that adolescents have learnt certain responses in relation to different life situations. Therefore they expect other people, including their peers to respond in a similar manner in which they have observed and experienced. This has resulted in adolescent's isolating themselves and further strengthening their beliefs in regards to common reactions and responses to people infected or affected with HIV/AIDS.

5.4 Adolescent's educational/ career development

5.4.1 Interruptions in school functioning

When considering the manner in which a child's overt behaviour manifests, a study conducted by Bennell, Hyde, and Swainson (2002) depicted that school functioning may become impeded amongst orphans and children affected with HIV/AIDS. Some of the pressing issues that have been highlighted by school teachers who have been having direct contact with the children have stated some of the contributing factors that cause huge impediments in the child's ability to progress well academically. Behavioural problems have been a source of tension between the child and the teacher as in most instances; teachers have regarded the child's behaviour to being unruly, disruptive and aggressive. In addition to the uncontainable behaviour it has been the case that children also tend to be withdrawn and can become quite tearful (Bennell et al., 2002). Poor concentration levels have been of concern as children have been seen sleeping in the classroom during teaching time. This has been mainly attributable to fatigue and hunger which negatively impacts on the children's ability to complete their homework's thus making it hard for them to perform at a level that is expected of them (Bennell et al., 2002). Since it has been depicted that children growing in a context whereby parents are not able to partake in certain tasks at home, that children end being the one's responsible for doing so therefore compromising their ability to attend wel at school (Anderson, 1999; Chamorro, 2004).

Issues pertaining to the illness being discussed at school as part of the learning curriculum and the adolescent having to concentrate in class bearing in mind the stressors that they are experiencing, can influence the adolescent's ability to cope efficiently at school or not. The following extracts illustrate the different aspects which may impact on the adolescent's functioning at school.

> *"I get tired at times and I sometimes sleep when the teacher is delivering the lesson. When the HIV topic was raised in class, sometimes I used to have a headache, then I would just run out of the classroom as I did not want to hear what was being spoken about." I would start crying…not knowing…sometimes I would cry hoping that it was going to be better. I became socially withdrawn, walking out of classrooms and crying if something really hurt me. At other times, I would even leave the school's premises."" (Interviewee # 3).*

Interviewee three elaborated upon her experiences in an upfront manner, making sharp eye contact with a sense of boldness noted. Her tone of voice suggested that she was not apologetic for not being able to pay attention and to fully concentrate in class. Instead it seemed that the interviewee understood the importance of attending school and did not allow herself to make excuses based on her compromised ability to be as fully present as other pupils were. For this interviewee she chose to strive forth in circumstances that were clearly not ideal for a student therefore depicting her resilience.

There were also difficulties expressed by the adolescent's in regards to not being able to cope as they struggled to process information taught in class that included topics related to HIV/AIDS. Interviewee three continued to express her inability to contain her emotions in the presence of classmates and her teacher due to sudden overwhelming emotions that she felt. As she spoke the interviewee's eyes were as if she was perplexed by the strong feelings that were intolerable to bear. These feelings may have been frightening for the interviewee and may have also contributed to the interviewee isolating herself in possibly believing that other people would not understand the amount of distress and loneliness that she is experiencing. Similar challenges were encountered by interviewee three who acknowledged the emerging interpersonal problems that were becoming evident in her life.

When the stressors became a prominent problem in regards to interview three's inability to be physically present school, it became inevitable for the adolescent to actually share with their mother the cause of their worries;

> *"When I thought about it (my mother being infected with HIV) I would continue crying. I even informed my mother that I struggle to cope when the topic of HIV is being discussed. My mother then sat me down and explained that it does not mean that one is suddenly going to die upon testing positive. ...However, I informed her that actually it is difficult for me as people usually speak as if a person is suddenly going to die." (Interviewee # 3).*

Interviewee three spoke in a very soft tone with her face downcast. At the moment it seemed that the interviewee's discussion about her difficulties to her mother was the last resort as she would not do or say anything otherwise that would further jeopardise her mother's health and overall functioning.

With disrupted lessons from school it became evident that interview three was missing out on her school work and the fact that other pupils had rejected her pleas for being assisted meant that she could not ask them to assist her. She explains the importance and source of motivation below;

> *"I actually failed last year during the first term. However, I told myself that I really needed to work hard during the second term. I told myself that it won't help me in any way to continue feeling ashamed as the most important thing for me is to work on my studies. This is because my mother used to tell me that I needed to study and pass my grades up until I finish school. Once I have accomplished this, I would be able to be independent. My mother always encouraged me to be independent as she also never liked being dependent on my father. (Interviewee # 3)*

Interviewee three further elaborated on the practicalities that she could not engage with at school which resulted in her unsatisfactory performance at school;

> *"It was in my first term that I would not even write in my answer sheet, for instance if we were writing a test or an examination. I would just leave the question paper as is. I would just ruminate about my mother and what it was that she was doing. So basically I would only answer questions that I knew, meaning that I would leave blank spaces for answers that I did not know. So it was at that point when my teacher realized this that she called to request to see my mother. However, I explained that my mother was ill and therefore could not come. The only other available person was my aunt who then went to have a meeting with my teacher. Feedback that was communicated by my aunt stated that I needed to free myself from all distressing thoughts in my mind." (Interviewee # 3).*

In as much as interviewee three is concerned about her academic functioning, the fact that it was not long after her mother had passed away, only exacerbated feelings of anxiety and possibly, shame. The interviewee's expression of helplessness in regards to her inability to free herself from being preoccupied with her mother's illness and subsequent death was something she could not change or control. Due to the noticeable suffering that the interviewee was experiencing, counselling services were organized so as assist her in regards to treating some underlying symptoms of depression that she was presenting with.

Counselling services may be of great benefit when considering that in most instances it can be challenging for a child to get support when they are affected by HIV/AIDS as when compared to adults. This is primarily due to the fact that in many African contexts, adults do not consider children as their equals when it comes to addressing important issues. Therefore this precludes adults from sharing their counsel with children who are in need of being helped in processing their emotions (Loubster, & Muller, 2006). Furthermore this is primarily perpetuated by the apparent need to keep the disclosure a secret and to share it with family members. However it has been depicted that the less pressure enforced on keeping the disclosure a secret, the better the opportunity for the adolescent to be helped and supported during this time (Helping children, 2012). Therefore in the context of the school it may be better for the parent to consult with the adolescent if they prefer to perhaps disclose to their class teacher who can then negotiate with the affected adolescent the best way they need to be supported. However this option was foreclosed in interviewee three's case as other pupils assumed a discriminatory stance upon learning about the disclosure. It may be that when disclosure occurs within a respectable confine with a trusted adult then the adult can with their knowledge of HIV/AIDS relay the information in a manner that may hopefully encourage other pupils to be accepting and supporting of the adolescent's situation (Helping children, 2012). Depending on the viability of this, it has been proven that other pupils may be able to comfort the adolescent affected in times of need and can even go to the extent of writing encouraging letters as well as recording and handing in messages of concern (Helping children, 2012).Therefore this depicts that there is still hope in regards to providing a more supportive environment for the adolescent which can also be out of the confines of their home which may be facilitated through effective communication channels. Hopefully this may result in stigma and discriminatory practices becoming less.

5.4.2 Pressure to accept maternal disclosure (and move on with life)

This was an additional theme which was unexpected but deemed important for purposes of this study. It may be argued that it takes courage to confront one's emotions and allow one to feel and make meaning in situations that are particularly anxiety provoking. It may be expected as depicted by the extracts below that in their efforts (especially family's) to protect the adolescent from experiencing further feelings of shame, the latter was encouraged to

distance themselves from unpleasant feelings. The extracts below give a much more detailed account of this phenomenon;

> *"The important thing really, is to be content with the situation and really to accept it. This will make it easier for my family and I to better support my mother. She (aunt) told me that I should accept just as my mother has accepted and that nothing will happen to her as she is as normal as other people. Moreover my aunt told me that it is not a big deal, thereafter I was fine and felt better. Even my twenty three year old sister used to tell me that at times this hurt her deeply but she has accepted. She said if all of us accept, then everything will be better for us. In all that I was doing for example, not coping well at school, I knew that I would worsen my mother's health as she will be stressing about me. I would certainly not like such things to happen." (Interviewee # 3*).

It is evident that maternal HIV disclosure not only impacted the adolescent's lives within the household only but also had an impact on other areas of their lives such as their functioning at school. However this is a huge concern as it is a known fact that education creates opportunities which better people's lives. Therefore adults who witnessed the adolescent's response may have thought that if there was no intervention implemented to assist the adolescent's then the impact of disclosure could create jeopardize their future.

Furthermore the extract above illustrates the anxiety apparent in actually trying to lessen the adolescent's pain and suffering without letting this be an obstacle in their lives. Interviewee three's expression was filled with less intensity and there was a noticeable contrast between the manner in which she spoke about her painful compromised ability to cope at school soon after the death of her mother and the manner in which she was currently expected to be strong by letting go of all the distressing memories. The interviewee's quick rate of speech and elevated volume resulted in her demeanour changing to being vibrant almost as if she was trying to minimise and thrive beyond the effects of being affected by HIV/AIDS. During one of the sessions she had with her counsellor the urgency to relinquish emotions linked with the death of her mother was of significance as is evident in her narrative;

> *"She also emphasized that my aunt is available to give me the same kind of life that I was given by my mother. It was not long after this conversation that I started feeling much better and had forgotten about my mother's death." (Interviewee # 3).*

Here the interviewee narrated her story without much feeling almost as if she was trying hard to convince herself to believe what she was saying.

Below, interviewee one recounted stories that were similar to interviewee's three attempt to distant herself from experiencing unpleasant emotions;

> *"…I would think about questions like, how did my mother contract this disease, but I would not focus too much on these thoughts. I would forget about it. I did not experience any stress. The thing with me is that, I accepted my mother's HIV status the first time around and also that I should not let that interfere with my studies. Currently, I am in grade eleven and I am certain that it will no longer affect me. I cannot feel sorry for myself…." (Interviewee # 1).*

Interviewee one was not engaging with her emotions and it may have been that this played a protective factor from exposing and having to process feelings of vulnerability, sadness and shame. It is apparent though that interviewee one does experience distressing thoughts but makes an effort to ignore these all the time. The interviewee denied any adverse feelings within herself thus denying herself the opportunity to process these feelings in a particularly meaningful manner. The interviewee spoke in a confident manner and it may be that if she allowed herself to feel sorry, she may have thought of herself to being weak could interfere with how she perceives herself, thus negatively impacting on her self-esteem.

Enforced acceptance seems to buffer against negative perceptions about oneself and may act as a short-term distraction for the adolescence which may be good as some adolescents were able to carry on doing well as school. However it is important that such feelings be worked through over time. Hence the need for counselling becomes imperative with special focus being based on the effects of having to process the illness of a parent. This may entail firstly, exploring ways in which the adolescent copes with dramatic mood changes which are commonly experienced by persons infected and affected by HIV/AIDS (Counselling for caregivers, 2007). Furthermore this implies exploring with the adolescent any distressing feelings felt when they are attending school. Secondly counselling could focus on the adolescent's experiences regarding family members or relatives who discriminate against them and the effects that this has on their lives (Counselling for caregivers, 2007). Lastly the need of exploring with the adolescent their concerns regarding the death of a parent becomes imperative as well (Counselling for caregivers, 2007).

6. Chapter Six: Conclusion and Recommendations

6.1 Introduction

This chapter forms the basis of the study's conclusion. The key aim and objectives will be discussed to give a comprehensive understanding to the findings of this study.

In retrospect the aim of the study was to explore the impact of maternal HIV-disclosure on adolescent's development. For an enhanced understanding of this phenomenon, this was done in particular reference to exploring the adolescent's relationship with their mother and the kinds of roles expected of them; adolescent's peers and other significant relationships as well as adolescents educational and/ or career development.

There has been previous research conducted focusing on adolescent's experiences following maternal HIV-disclosure; however this has mostly been done and analysed through the maternal lens. This research has looked into adolescent's experiences through their own perspective thus providing unique individual accounts.

6.2 Summary of the findings

There have been three dominant themes. The first theme has been about adolescents and maternal relationships which have raised concerns regarding reasons that make adolescents weary of their mother's love following HIV-disclosure. Some of the pertinent concerns that have been raised include not having one's basic needs met which further increases the adolescent's susceptibility to vulnerability. Maternal love was felt by the adolescent's to be threatened by substance abuse, parental promiscuity as well as poor compliance to treatment which proves to have added to adolescent's feelings of helplessness. This was evident in adolescent's apparent impending fear concerning their mother's death. Furthermore these concerns contributed to adolescent's experience of disturbing images which made increased their feelings of vulnerability and anxiety. Hence it became clear from the narratives that even though mother's deemed the abuse of alcohol to be one way in which they could cope with living with the illness, however it became clear that alcohol abuse only strained and took away the security and safety once felt in the dolescent-maternal relationship.

Moreover adolescent's feelings of helplessness were perpetuated by perceptions held in society about women living with HIV/AIDS which is mostly stigmatising thereby ostracizing

the infected/ affected person. This has been seen to have the effects of feeding into the mother's self-sabotaging behaviour as it became apparent that the mothers' may be blaming themselves and therefore their behaviour may be understood as a way of punishing themselves. It may be that with self-sabotaging behaviour they feel that they are bad and deserve all the bad things coming from society and from themselves. However this not only impoverishes their health but impoverishes their children's well-being.

It has been depicted that it is through these experiences that adolescents have seemingly learnt to appreciate their mother's presence in their lives despite the challenges encountered. Furthermore it became evident that adolescents realised the difficulty experienced by their mother's to an extent that it can be assumed that this motivated them to take better care of themselves so that they can be in a position to avail themselves to their mothers. Subsequently this has been seen to have taken place in the form of role reversal which seems to have in some instances enhanced the adolescent-maternal relationship but also seems to have taken away from the adolescent the space for self reflection in terms of knowing oneself as an individual, separate from the mother.

Pertaining to adolescents relations with their peers and significant others it became apparent that adolescents felt different or rejected from peers due to feeling that they do not fit in conversations that peers of their age usually engage in. It may be argued however that these are conversations that adolescents normally engage with; however, these conversations are perceived differently by the adolescent affected by HIV/AIDS. The main reason for this includes that the adolescent affected often tends to think that others are not respecting or understanding enough of their situation. Furthermore the opportunity to freely discuss one's difficulties certainly seems to be an idea that is not commonly embraced thus further isolating the adolescent with their hardships.

Since it has been clear from the extracts that the adolescent's are really fond of their mothers as they share a close relationship, therefore the death of the mother may even symbolise not only the effects of stigma and discrimination from peers but may also be part of the bereavement process of which the adolescent may not be entirely aware of.

In regards to adolescent's educational/ career development it became evident that taking into considerations stressors that inevitably result from the themes that have already been discussed above, adolescents tend to experience challenges that makes it difficult for them to

cope efficiently at school. Therefore as a means of counteracting these effects it has been apparent that counselling services could be of great benefit only if the process is respected in regards to not putting pressure on the adolescent to overcome the stressors they are experiencing.

6.3 Limitations of the study

It would have been really informative and would have really contributed to theoretical knowledge had there been rich data obtained from a male participants. Had this been the case, the study would have had the opportunity to look further into whether there would have been similarities or differences regarding males and females perspective on maternal HIV-disclosure. Moreover it would have been insightful to explore whether gender dynamics impacted had an influence in regards to adolescent's response to maternal HIV-disclosure. Lastly

6.4 Recommendations of the study

It would be good to avail more support systems for mothers living with HIV/AIDS. Interventions specifically tailored towards looking further into adaptive and maladaptive coping strategies would be useful in addressing and hopefully reducing tensions that result in the adolescent and maternal relationship. It is a concern since unprocessed emotions have proven to be detrimental for the mother and their relationship with their children. For an example, anger outbursts and acts of self sabotage are particular issues which can be looked into in the context of individual or group therapy for mothers living with HIV/AIDS. It is hoped that through this adolescents will be at a much better position to cope more effectively with the inevitable stressors that result due to the disclosure and the timing of the disclosure which impacts on their developmental phase.

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APPENDIX F

INFORMATION SHEET FOR THE ORGANISATION

I [ ] (name) as a representative of acknowledge that Sibongile Sibanyoni has explained her study of the experiences of adolescents following maternal HIV disclosure. We believe that her research sufficiently protects the adolescents she is studying, and we have agreed to allow her access to adolescents who are active participants to the programmes for her interviews.

Signed:_____ Date:_____

APPENDIX G: PARTICIPANT INFORMATION SHEET

Good day. My name is Sibongile Sibanyoni. I am a student at Rhodes University currently studying Masters in Clinical Psychology. I am doing a research project as part of my degree requirements.

Nature and purpose of the research:

The proposed study explores the adolescents' experiences following maternal HIV-disclosure which specifically focuses on intricacies evident in the adolescent's life such as relationships with their mothers, relationships with peers, school functioning as well as acceptance or not of the disclosure.

Voluntary and confidential participation:

I would like you to take part in my study. This will mean that I will have one interview with you for approximately one hour. You do not have to take part in this study. If you do not want to take part, nothing will be held against you. If you do want to take part, but then later change your mind, you can stop at any timed in the study and your information will be taken out of the study. If you do take part in the study, I will take out any information (such as your name) that would let other people know that you took part in the study.

Interview procedure:

I will interview you in a place that is convenient to you. The interviews will take approximately an hour. You will have the right to stop the interview at any time. If you agree for the interview to be tape-recorded, I will record the interview. You will be requested to sign a separate consent form for this. The tapes will be kept in the Psychology Department and destroyed after a period of five years.

My contact details:

Should anything be unclear or if you would like more information about this study, please do not hesitate to contact me via email or telephonically. My email address is s.sibanyoni@ru.ac.za and my telephone number is 073 970 3304.

Alternatively, you can contact my supervisor Ruby Patel at email address r.patel@ru.ac.za or telephone number 082 045 0620.

Thank you for taking time to consider participating in the study. If you do adree to take part, please fill out the attached form.

Yours sincerely,

Sibongile Sibanyoni

APPENDIX H

<u>Example</u> of an agreement form for use in conjunction with the *Ethical Standards Research Protocol* - Remember to give participants a signed copy of this agreement (and keep one).

RHODES UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

AGREEMENT BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT

Updated 26 January 2011

I (participant's name) _____ agree to participate in the research project of (researcher's name) _____ on (short title / topic of research project).

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a/an (Honours/Master's/PhD) _____ degree at Rhodes University. The researcher may be contacted on _____ (cell phone) or _____ (email). The research project has been approved by the relevant ethics committee(s), and is under the supervision of Prof/Dr/Ms/Mr _____ in the Psychology Department at Rhodes University, who may be contacted on _____ (office) or _____ (email).

2. The researcher is interested in (short description of the main focus areas of the research / relationship between variables under investigation).

3. My participation will involve (short description of the nature of participation required and the anticipated duration of this participation).

4. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.

5. I am invited to voice to the researcher any concerns I have about my participation in the study, or consequences I may experience as a result of my participation, and to have these addressed to my satisfaction. *A counselling centre may be contacted for further support on _____ (telephone) - [add this information if there is the slightest risk of distress, embarrassment or offence as a result of participation].*

6. I am free to withdraw from the study at any time - however I commit myself to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not originally anticipate.

7. The report on the project may contain information about my personal experiences, attitudes and behaviours, but that the report will be designed in such a way that it will not be possible to be identified by the general reader.

Signed on (Date):

Participant: _____ Researcher: _____

APPENDIX I

Rhodes University – Department of Psychology

USE OF TAPE RECORDINGS FOR RESEARCH PURPOSES
—
PERMISSION AND RELEASE FORM

Participant name & contacts (address, phone etc)	
Name of researcher & level of research (Honours/Masters/PhD)	
Brief title of project	
Supervisor	

Declaration

(Please initial/tick blocks next to the relevant statements)

1.	*The nature of the research and the nature of my participation have been explained to me*	verbally	
		in writing	
2.	*I agree to be interviewed and to allow tape-recordings to be made of the interviews*	audiotape	
		videotape	
3.	*I agree to take part in and to allow tape-recordings to be made.*	audiotape	
		videotape	
4.	*The tape recordings may be transcribed*	without conditions	
		only by the researcher	
		by one or more nominated third parties:	
5.1	*I have been informed by the researcher that the tape recordings will be erased once the study is complete and the report has been written.*		
5.2	*OR I give permission for the tape recordings to be retained after the study and for them to utilised for the following purposes and under the following conditions:*		

Signatures

Signature of participant		*Date*
Witnessed by researcher		

APPENDIX J: INTERVIEW SCHEDULE

First name:

Date:

Referral organisation:

Biographical Details

1. Gender:
2. Age:
3. Do you go to school?
4. What school do you go to?
5. What grade are you in?
6. Who stays with you in your household? Please provide a brief description of what it is that each person does and the corresponding age.
7. How were you informed/ disclosed to about your mother's status?
8. How did you feel subsequent to being disclosed to?
9. How would you describe your relationship with your mother prior to and subsequent to being disclosed to?
10. How would you describe your relationships with others subsequent to being disclosed to?
11. Subsequent to being disclosed to, did this have an impact in terms of how you understood your role within the household?
12. How would you describe your school functioning subsequent to being disclosed to?