Psychological variables and maternal HIV status disclosure to young uninfected children

By

Amukelani Jennifer Hlungwani

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Supervisor: Prof. M. Visser

Co-supervisor: Ms A. Thomas

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Declaration

I *Amukelani Jennifer Hlungwani*, declare that this mini-dissertation entitled: *Psychological variables and maternal HIV status disclosure to young uninfected children* is my own work. All of the sources used have been duly acknowledged using the American Psychological Association (6th edition) referencing guidelines. This mini-dissertation is submitted in partial fulfilment of the requirements for the degree of Masters of Arts in Research Psychology at the University of Pretoria, South Africa. It has not been submitted before for any degree or examination at any other university.

Signature: Amukelani Jennifer Hlungwani Date: 12 June 2017

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Abstract

Mothers living with HIV are faced with the dilemma of when and how to disclose their HIV-positive status to their young uninfected children. In this study, baseline data from the Kgolo Mmogo project was used to understand this dilemma using a South African sample in the city of Tshwane. The researcher aimed to compare mothers who disclosed their HIV status to their young children with mothers who did not disclose in terms of self-reported psychological variables (depression symptoms, coping style and parenting stress) using a Mann-Whitney U test. In addition, the research also investigated which maternal socio-demographic variables (mother's age, employment status, marital status and level of education) are significantly associated with maternal HIV status disclosure using a Chi-square test of independence. This research consisted of 97 mothers grouped according to their disclosure status (n = 47 mothers that disclosed and a randomly selected sub-sample n = 50 of the 356 non-disclosing mothers). The following instruments were used: the Centre for Epidemiological Studies-Depression scale, the Brief COPE scale, the Parenting Stress Index Short Form and the Kgolo Mmogo questionnaire. In the findings, the marital status of mothers was significantly associated with HIV status disclosure. Single mothers disclosed significantly more than mothers who were married or had partners. The age, educational level and employment status of the mothers were not significantly associated with maternal HIV disclosure status. Furthermore, the results revealed that mothers in both groups (disclosing and non-disclosing) reported high levels of depressive symptoms and parenting stress. The groups did not differ significantly with regards to these variables. Similarly, while overall coping style was not significantly different between the two groups of mothers, the disclosing mothers were significantly more likely to use support seeking and behavioural disengagement as a coping style, while non-disclosing mother were more likely to engage in self-blame as a coping strategy. This study provides evidence that psychosocial support services should become an integral part of HIV and AIDS routine care as

this may improve coping and reduce psychological distress and lead to higher rates of disclosure. This is important because maternal disclosure has documented benefits for both mother and child.

Key words: Maternal HIV status, maternal HIV disclosure, depression symptoms, coping style, coping strategy, parenting stress, socio-demographic characteristics.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

This study is an investigation into psychological variables associated with disclosure and non-disclosure such as depression symptoms, coping style and parenting stress, in families living with HIV where mothers have disclosed their HIV status to their young and uninfected children as opposed to families where there has been no disclosure of maternal HIV status to the young uninfected children.

The first chapter outlines the background to the research and presents the problem statement. It also addresses the research questions and the significance of the study. The chapter furthermore outlines the methodology applied as well as the focus of the subsequent chapters.

1.2 Problem statement

South Africa has one of the highest HIV infection rates in the world (UNAIDS, 2016). The majority of people living with HIV are female and most of them are of child bearing age (Shisana, Rehle, Simbayi, Zuma, & Jooste, 2009; Shisana et al., 2014). Improved access to Antiretroviral Therapy (ART) makes it possible for parents living with HIV to lead a healthier and longer life (Oguntibeju, 2012). This enables them to take care of their children for a longer period of time (Bor, Herbst, Newell, & Bärnighausen, 2013).

The Prevention of Mother to Child Transmission (PMTCT) program has proven to be highly successful in the sub-Saharan African region. The success of this program has resulted in a decrease in the number of children who are born infected with HIV (Barron et al., 2013). Improved access to ART in conjunction with the excellent results of PMTCT has also resulted in a large number of parents living with HIV whilst raising HIV negative children (Rochat, Mkwanazi, & Bland, 2013).

Mothers living with HIV are faced with the dilemma whether or not they should disclose their HIV status to their children (Chi & Li, 2013). Furthermore, these mothers do not know when and how they should disclose their HIV status (Goldberg & Short, 2016). Maternal disclosure of HIV status to children is a complex issue as it involves maternal and child characteristics, the family environment, culture as well as the stigma communities attach to HIV (Dass-Brailsford, Eckman, & Kwasnik, 2014).

The World Health Organization (WHO) released guidelines for healthcare workers to aid caregivers in disclosing HIV status to children up to the age of 12 (World Health Organization, 2011). The guidelines were drafted due to a lack of consensus on how, when and under what conditions healthcare workers should assist HIV affected families in disclosing the HIV status of the parents to the children. Mkwanazi, Rochat, Imrie, and Bland (2012) conducted a literature review study to synthesize current research on maternal HIV status disclosure to young uninfected children. Their results revealed that the rate of HIV status disclosure to children varies across studies and that it ranges from as low as 11% to as high as 84% across a number of studies in different countries. Research conducted in the sub-Saharan region shows that mothers are willing to disclose their HIV status to their children of primary school-going age (Mkwanazi et al., 2012). However, for a variety of reasons they feel inadequately equipped to do this. Mothers living with HIV are unsure about the appropriate age at which they should disclose their HIV status to their children. They also do not feel confident to answer questions about HIV from their children and are furthermore concerned about how their children will react to the news. In South Africa, many children are raised in an HIV exposed environment. Disclosure of parental or maternal HIV status has, therefore, become a significant issue (Madiba & Matlala, 2012).

1.3 Research question

The main aim of this study is to investigate whether there are differences in depression symptoms, coping style and parenting stress present in mothers who have disclosed their HIV status to their young uninfected children as opposed to those mothers who have not disclosed their HIV status to their children. The secondary aim is to explore which maternal socio-demographic characteristics (mother's age, employment status, marital status and level of education) are associated with maternal HIV status disclosure to young uninfected children. It is important to understand the context in which disclosure takes place and how mothers deal with the disclosure of their HIV status.

Research question: Are there significant differences in psychological variables between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children?

Sub-question1: Are there significant differences in depression symptoms between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children?

Sub-question 2: Are there significant differences in the coping style of mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children?

Sub-question 3: Are there significant differences in parenting stress where mothers have disclosed their HIV status and where mothers have not disclosed their HIV status to their young uninfected children?

Sub-question 4: Which maternal socio-demographic characteristics (mother's age, employment status, marital status and level of education) are associated with maternal HIV status disclosure to young uninfected children?

1.4 Overview of methodology

To investigate the research question, an existing database of the Kgolo Mmogo project, a randomised controlled trial conducted in Tshwane (Eloff et al., 2014), was used. The project addressed the effect of maternal HIV on the well-being of young uninfected children between the ages of 6 and10 (Sipsma et al., 2013) as well as the effect of a resilience intervention on the well-being of the uninfected children (Eloff et al., 2014).

One of the questions posed was whether mothers disclosed their HIV status to their young uninfected children at baseline. This part of the data has not yet been analyzed. The current research is thus a secondary analysis of the Kgolo Mmogo database. In this study a quantitative approach was used to investigate psychological differences in mothers who disclosed and in those who did not disclose their HIV status to their young uninfected children. To investigate differences in depression symptoms, coping style and parenting stress between the two groups, a Mann-Whitney U test was performed on the data.

1.5 Significance of the study

There are two main reasons why this research is significant. Firstly, very little research has been done on maternal disclosure of HIV status to uninfected primary school-aged children in the South African context (Rochat et al., 2013). Previous research in this field focussed on how disclosure of maternal HIV impacted on a child's psychological functioning (Sipsma et al., 2013). This study shifts the focus to investigate maternal psychological functioning, that is to investigate the association between maternal psychological functioning and the associations between psychological functioning and HIV disclosure or non-disclosure to young uninfected children.

The objective of this research was to investigate whether there were differences in psychological variables (depression symptoms, coping style and parenting stress) between the two groups of mothers, i.e. those who disclosed and those who do not disclose their HIV status. Such information would be helpful in forming content for future research directed at planning interventions to promote and optimize maternal disclosure. There is a need for culturally and developmentally appropriate interventions within the sub-Saharan African context to support parents in undertaking disclosure of HIV status (Li, de Wit, Qiao, & Sherr, 2015). This research sets out to give an overview of maternal disclosure of HIV status in the South African context. This should be particularly useful, considering that South Africa has one of the highest HIV infection rates in the world.

The second reason for this study is that research indicates that an HIV diagnosis does not only affect the mother individually but also impacts on the family as a whole, as mothers are the primary caregivers in most of the families (Murphy, Armistead, Marelich, Payne, & Herbeck, 2011). Therefore, this study will create awareness of the complexity of maternal HIV disclosure and provide more information on the experience of psychological variables by the two categories of maternal HIV status disclosure. It will also provide an indication of whether or not mothers living with HIV report psychological variables differently if their HIV status is disclosed to their young children at baseline. This research will, in essence, give an indication of what is the psychological functioning of mothers living with HIV and ascertain whether psychological functioning differs by maternal disclosure of HIV status.

1.6 Main concepts

1.6.1 HIV/AIDS

HIV is an acronym for Human Immunodeficiency Virus. AIDS is an acronym for Acquired Immunodeficiency Syndrome. According to WHO, HIV can be defined as a retrovirus which

infects, destroys and impairs the cells of the immune system. The immune system becomes weaker and the individual living with HIV becomes more susceptible to other infections or diseases such as tuberculosis. The most advanced stage of HIV is AIDS. It can take many years for an individual living with HIV to reach this stage. HIV is transmitted through body fluids. The most common route of transmission is during unprotected sexual intercourse with a person who is infected with the virus. HIV transmission can also take place through transfusion of contaminated blood (blood containing the virus) or by sharing contaminated needles. HIV can also be passed on from mother to child during pregnancy, childbirth and breastfeeding (World Health Organization, 2016). It is important that people are informed on HIV and AIDS, especially families who live with a member who is infected with the virus. Disclosure of one's HIV status is equally important as it is can be seen as a method of HIV prevention, and when families are knowledgeable about HIV the members can provide social support to the infected individual (Atuyambe et al., 2014).

1.6.2 Antiretroviral therapy (ART)

ART is the medication that suppresses a retrovirus. ART is taken by individuals living with HIV to aid the functioning of the immune cells. The ART treatment regime will prolong the process of HIV from advancing to AIDS (World Health Organization, 2016).

1.6.3 HIV status disclosure

Disclosure refers to a process whereby a person verbally communicates or shares his or her personal information with another person (Qiao, Li, & Stanton, 2013a). The level of disclosure may vary and range from non-disclosure, partial disclosure to full disclosure. Non-disclosure is when an individual does not reveal to others that he/she is living with HIV or may become ill. Partial disclosure refers to the process of revealing that one is ill but not disclosing that one

is has a positive HIV status. Full disclosure is the process whereby an individual reveal to others that he/she is living with HIV (Wiener, Mellins, Marhefka, & Battles, 2007).

1.6.4 Depression

Depression is a disorder that involves an individual's mood and thoughts. At some point in time everybody goes through a period in life where they occasionally feel sad or "blue". However, these feelings are usually fleeting and may pass after a couple of hours or days. A depressive disorder is not just a passing mood, but persistent feelings of sadness and worthlessness and a lack of desire to engage in formerly pleasurable activities (Gallo & Rabins, 1999; Andersen, Kagee, O'Cleirigh, Safren, & Joska, 2015). According to the *Diagnostic and Statistical Manual of Mental Disorders 5th edition*, people who experience depression often experience fatigue and insomnia and may experience loss of appetite and concentration (American Psychiatric Association, 2013). A depressive disorder is a complex mind/body illness which interferes with an individual's ability to do things that he or she normally could do well. Depression negatively affects not only the individual but also those who care about them. Depression is one of the most common mental disorders (Sharif et al., 2011). Fortunately, it is treatable with a combination of therapy and antidepressant medication (American Psychological Association, 2016).

1.6.5 Coping and coping style

Coping refers to constant behavioural and cognitive efforts that an individual employ in order to deal with and manage stressors (Folkman, 2013). Coping can be categorised as either active or avoidant coping. Active coping is when an individual engages in behavioural and cognitive attempts to deal with and change a stressful event. It includes coping strategies such as problem solving (Smith, Feaster, Prado, Kamin, Blaney, & Szapocznik, 2001). Avoidant

coping is when an individual engages in behavioural and cognitive actions to avoid dealing with a stressful event (Kotze, Visser, Makin, Sikkema, & Forsyth, 2013; Smith et al., 2001).

1.6.6 Parenting stress

Parenting stress (Abidin, 1990) refers to the difficulties that arise from being a parent (Murphy, Marelich, Armistead, Herbeck & Payne, 2010). Parenting stress forms part and parcel of the parenting experience. This type of stress arises when parenting demands exceed the expected and available resources of individuals to successfully engage in the parenting role (Rochat, Netsi, Redinger, & Stein, 2017). Parents have to manage their busy schedules, balance their work responsibilities and household duties whilst raising children at the same time (Rochat et al., 2017). This act of balancing and managing different roles results in parenting stress (Murphy et al., 2010). The Parenting Stress Index (PSI) is a self-report measure designed to identify and screen potentially dysfunctional parent-child systems. It focuses on three major areas of stress: child characteristics, parent characteristics and situational/demographic life stress (Abidin, 1990).

1.7 Chapter overview

The research is presented in five chapters. Following the introduction, the second chapter is a literature review of maternal disclosure of HIV status to young uninfected children. The third chapter discusses the research methodology employed in the study with reference to sampling, measurement instruments and data analysis techniques applied. The fourth chapter presents the findings of the study. The last chapter presents a discussion of the main findings in context of current literature, the limitations of the study, recommendations for future research and conclusions.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL APPROACH

2.1 Introduction

This chapter is essentially a literature review of maternal disclosure of HIV status to uninfected children. The first part of the review addresses women's vulnerability to HIV as well as the community norms that complicate HIV status disclosure. The second part of the review addresses research on women's disclosure of their HIV status to their partners and family members. Thereafter the study will address maternal HIV status disclosure and associated factors that may distinguish mothers that disclose their HIV status to their young children as opposed to those who do not. The socio-ecological approach will serve as a basis for understanding the dilemma mothers face with regards to the question of whether or not they should disclose their HIV status to their children.

2.2 The dilemma of women disclosing their HIV status.

The sub-Saharan region is the most HIV affected area in the world and South Africa has one of the highest adult HIV prevalence rates in the world (UNAIDS, 2013). The HIV prevalence rate for the total South African population is estimated at 11.2%. In 2015 the total number of people living with HIV in South Africa was approximately 6.19 million (Statistics South Africa, 2015). This makes HIV a prominent health concern in South Africa (Ramjee & Daniels, 2013; UNAIDS, 2013). Young women between the ages of 15 and 24 have a higher infection rate than males of the same age group (Statistics South Africa, 2015). This is confirmed in statistics reported by UNAIDS (2014) where women accounted for 58% of the total number of people living with HIV in sub-Saharan Africa. As more women than men are infected with HIV it compounds the complexity of the problem as they have to cope with the dilemma of how to disclose their HIV status to their loved ones.

The biological vulnerability of women to sexually transmitted infections puts them at a higher risk of contracting HIV than their male counterparts. Cultural, social and economic

factors reinforce the biological vulnerability of women as these factors limit their ability to protect themselves from infection (Shisana et al., 2014). For example, in a society where the male sexual needs are considered as overriding that of their female partners, it becomes difficult for women to stipulate fidelity and to negotiate strategies for safe sex or no sex at all (Department of Health, 2007). Economic factors also play an important role in strategies to negotiate safe sex or no sex. For example, a woman who is financially dependent on her partner might like to engage in safe sex, however, if her partner refuses she will end up agreeing to his terms because he is seen as the provider. As a result, this has a major impact on the protection of women's health (Paterson, 1996; Susser, 2011). Most women living with HIV have been primarily infected through heterosexual intercourse (Department of Health, 2007; Shisana et al., 2014). Condom use, whether male or female, depends on male co-operation. It becomes difficult for women to negotiate condom use because of the traditional attitudes and stereotypes in which women are deemed as subordinate to men; the difficulty to negotiate safe sex is further exacerbated by social and economic inequality between men and women. This puts women in a difficult position where they cannot independently protect themselves from infection (Leclerc-Madlala, Simbayi, & Cloete, 2009). There is a culture of silence around issues of sex and sexuality in most societies and women are taught that they should take care of their reputation as 'proper and reproductive women' (Department of Health, 2007; Leclerc-Madlala et al., 2009). Some cultures prescribe that 'good women' are those that have silent opinions about issues regarding sex and they should be passive in sexual interactions with men (Department of Health, 2007). If women disclose their HIV status, they may not be deemed as of good reputation due to the stigma associated with HIV infection (Department of Health, 2007).

The role of a woman as a caretaker of her family and a responsible 'nurturer' can have a negative impact on the health of women living with HIV. Women living with HIV will continue

with the day to day struggle to care for their spouses and children in their pursuit of being a responsible 'nurturer'. They often do this at the expense of their own health (Susser, 2011). Cultural factors which influence beliefs and values regarding courtship, sexual orientation as well as norms for gender and marital relations, influence the perception of HIV and AIDS in African societies (Leclerc-Madlala et al., 2009). It is important to understand the impact of culture on the perception of HIV, as it influences decisions on HIV status disclosure.

HIV-related stigma and discrimination can be defined as acts of prejudice, negative attitudes and abuse directed at people living with HIV and AIDS (AVERT, 2016). Stigma has existed throughout history and can be defined as a disgrace associated with a particular circumstance, quality, or person (AVERT, 2016). The stigma attached to HIV is usually based on fear of the disease and the unknown factors associated with the disease. It is rooted in social processes such as gossip in communities and differential allocation of resources, such as poor treatment in healthcare and educational settings by public servants (AVERT, 2016). HIV-related stigma is embedded in social norms and it can be a form of social control whereby people who deviate from the social norms are punished by means of isolation and victimization (Mahajan et al., 2008). This is particularly true for women. As indicated, women are held at a higher 'moral' standard and it is the norm for a woman to be expected to keep up her reputation as a 'good' woman (Department of Health, 2007). Research indicates that HIV-related stigma has an impact on HIV and AIDS care because it interferes with prevention, diagnosis and treatment (Mahajan et al., 2008). A positive HIV diagnosis for a woman exposes her to significant risks such as rejection, isolation and discrimination as a result of stigmatisation of HIV infection and may negatively impact her social and economic status (Antelman et al., 2001). Because of the stigma associated with HIV, women can be labelled as sexually promiscuous, sex workers, unfaithful to their partners or drug users (Ostrom, Serovich, Lim, & Mason, 2006). Women in developing countries have cited fear of accusations of infidelity, abandonment, discrimination

and violence as barriers to the disclosure of their HIV status to their partners (Medley, Garcia-Moreno, McGill, & Maman, 2004). HIV-related stigma and discrimination create a culture of silence in people living with HIV and AIDS because they fear isolation and rejection from family and community members. In addition, stigma fosters denial and secrecy in people living with HIV, thus creating a barrier to HIV testing and access to treatment (Mbonu, van den Borne, & De Vries, 2009). Social and economic inequality in heterosexual relationships have resulted in some women living with HIV turning to men for financial assistance while not disclosing their HIV status due to fear of rejection (Medley et al., 2004; Susser, 2011). Social norms thus create a context for the dilemma women experience around HIV status disclosure.

Another factor is that South Africa has the largest ART rollout programme in the world (Madiba & Matlala, 2012). The life expectancy of people living with HIV has increased since the inception of ART (Fisher & Cooper, 2012; Shisana et al., 2014). Access to ART resulted in HIV being managed as a chronic disease, provided that the patients adhere to treatment (Degroote, Vogelaers, & Vandijck, 2014; Madiba & Matlala, 2012; Psaros, Remmert, Bangsberg, Safren, & Smit, 2015). As of September 2016, all South Africans living with HIV and AIDS are eligible for ART regardless of their CD4 count (Child, 2016). To access ART health care professionals, require that a person living with HIV disclose his/her status to at least one person to support them with ART adherence (Degroote et al., 2014; Madiba & Matlala, 2012). In the era before ART there was a low rate of HIV status disclosure by women due to fear of stigma and discrimination (Antelman et al., 2001; Patel et al., 2012). The availability of ART has, however, changed the scenario. Research shows that individuals living with HIV disclose their status to at least one person and that those on ART have better adherence due to social support from family and friends (Patel et al., 2012). As a consequence of being part of the ART programme, it becomes more difficult for a person to conceal his/her HIV diagnosis. This resulted in higher disclosure rates (Chaudoir & Fisher, 2010). HIV status disclosure has

benefits in that it lowers social stigma in the community and contributes to improving the individual's self-esteem and mental health (Patel et al., 2012). Most of the research conducted around HIV status disclosure focused on partner disclosure. In the next section factors that influence the disclosure of HIV status by women to their partners and significant family members are discussed.

2.3 Factors influencing women's HIV status disclosure

Disclosure of HIV status to significant others and family is highly promoted as it is seen as the first step in securing support from family members. Disclosure of HIV status is also important to bring about change in a person's sexual behaviour and HIV management (Crankshaw et al., 2014). The support received from significant others has a positive influence on the overall health, quality of life as well as the treatment adherence of individuals living with HIV (Crankshaw et al., 2014). Disclosure of one's HIV status is a complex phenomenon as it is mediated by a variety of factors such as the individual's psychological state, his/her communication skills, the relationship with the intended disclosure recipient as well as the fear of being stigmatized by others (Crankshaw et al., 2014).

HIV status disclosure is an important factor in prevention strategies to curb the spread and transmission of HIV and AIDS to one's partners and children (Batte, Katahoire, Chimoyi, Ajambo, Tibingana, & Banura, 2015). Therefore, most research conducted on women's HIV status disclosure involves disclosure to their partners. HIV status disclosure to partners is associated with benefits to the infected woman. She can receive social support from her partner and other loved ones such as family members (Crankshaw et al., 2014). In addition, HIV status disclosure is a prevention strategy because the infected woman can get access to HIV care and change sexual risk behaviour. It creates an awareness of the need to change sexual risk behaviour, especially for partners who have not tested for HIV (Batte et al., 2015).

Medley et al. (2004) conducted a meta-analysis to synthesize the rates, barriers and outcomes of HIV status disclosure among women in developing countries. Disclosure rates varied between 16.7% and 86%. In attempting to understand why disclosure rates vary within different populations, several studies have looked at the relationship between socio-demographic characteristics of women and HIV status disclosure. This led to the identification of several factors relating to HIV disclosure in sub-Saharan Africa:

- Age: In the sub-Saharan region women younger than 24 years are more likely to disclose their HIV status to partners than older women (Medley et al., 2004). This was confirmed by research in other parts of the world (Ahn, Bailey, Malyuta, Volokha, & Thorne, 2016).
- Socio-economic status: Research conducted in Tanzania revealed that women who had a low-wage employment were less likely to disclose their HIV status to their partners (Antelman et al., 2001). In a South African study non-disclosure of HIV status to partners was significantly associated with having lost a job (Simbayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007).
- Marital status: Ostermann et al. (2015) found in a Tanzanian sample that individuals who were married were more likely to disclose their status to at least one household member. Women who were married or cohabiting were more likely to disclose their HIV status to their partners as compared to those who were single (Batte et al., 2015).
- Educational level: In Uganda, women with a secondary education or higher were more likely to disclose their HIV status, as compared to women who had less or no education (Batte et al., 2015). The same result was found in other developing countries in the sub-Saharan region. Women with a higher level of education were more likely to share their HIV status results with their partners than women who were illiterate or who had no schooling (Medley et al., 2004).

Women in developing countries who are unable to disclose their HIV status have cited fear of abandonment, rejection and discrimination, violence, upsetting family members, and accusations of infidelity as reasons for not disclosing their HIV status to their partners (Medley et al., 2004). Variations in disclosure rates to partners thus reflect the influence of socioeconomic and gender factors on the disclosure patterns (Bott & Obermeyer, 2013).

The research cited addressed the association between disclosure and women's socio-demographic variables in the context of disclosing HIV status to partners. In this research socio-demographic factors associated with a mother's decision to disclose or not disclose her HIV status to her young children will be investigated. This decision is seen as a reflection of how she experiences and deals with the diagnosis in her everyday life (Liamputtong & Haritavorn, 2014). As stated above in the aims and objectives section, the secondary aim of this study will be to determine if there is a significant association between maternal HIV status disclosure to young uninfected children and the following socio-demographic factors: the mother's age, employment status, marital status and level of education. It is important to consider the context of women's lives as they are faced with the decision whether or not to disclose their HIV status to their children.

2.4 Maternal HIV status disclosure.

A large number of parents living with HIV and AIDS are raising HIV negative children (Rochat et al., 2013). Maternal disclosure of HIV status to their children who are infected or uninfected is an increasingly important topic related to maternal mental health, children's health, parenting and custody planning as well as family relationships (Qiao et al., 2013a). Mothers living with HIV need help and support to raise their HIV uninfected children. One of the main challenges confronting mothers living with HIV is disclosing their HIV status to their children. Parents with pre-school and primary school-aged children seem to experience greater difficulty in disclosing their status to their children (Qiao et al., 2013a). They face additional

worries about whether the child is old enough to understand the HIV diagnosis, how the child will react and whether the child will keep the mother's HIV status a secret (Murphy, 2008; Qiao et al., 2013a).

2.4.1 Factors influencing maternal disclosure

There is a low rate of maternal HIV status disclosure to children worldwide (Qiao et al., 2013a). Armistead et al. (2001) conducted a study to investigate whether mothers were telling their HIV uninfected children about their HIV status. The results indicate that there were a small percentage (30%) of mothers who disclosed. The decision to disclose is made on a child-to-child basis. Mothers were more likely to disclose to female and older children (Armistead et al., 2001). Qualitative research reveals that parents prefer to disclose to a girl child because she might help with household responsibilities when the mother falls ill or becomes hospitalised (Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008). Mothers also chose to disclose their HIV status to an older child because they believed the child to be more mature in understanding the diagnosis (Geiselhart, Gwebu, & Krüger, 2008). Tiendrebeogo et al. (2013) argue that it is the mother's *perception* of her child's maturity that influences her decision to disclose. Their research shows that some parents who have children older than 18 still considered them too "young" for parental disclosure of HIV status. In contrast, other parents who have children who are "young", around the age of 7, have disclosed their HIV status because they feel their children are mature enough to deal with the HIV diagnosis (Tiendrebeogo et al., 2013). This argument reiterates Armistead's (2001) findings that maternal disclosure of HIV status is made on a child by child basis.

Murphy's review (2008) of research about maternal disclosure of HIV status to uninfected children was conducted in the United States of America (USA). The review focused on factors that influence disclosure or non-disclosure, characteristics of children who have been disclosed to and factors that influence children's reaction to disclosure. The results revealed that in some

cases maternal health was a factor affecting a mother's decision to disclose her HIV status. Maternal illness resulted in mothers needing assistance from children in the household; therefore, they disclosed their HIV status. Children's queries with regards to maternal health could also influence disclosure. Children become aware that their mothers are taking medication and this consequently gives rise to questions (Murphy, 2008). Findings with regards to children's age and gender are consistent in the literature, as mothers disclose more often to an older or a female child (Armistead et al., 2001; Murphy, 2008).

The review of Qiao et al. (2013a) on parental disclosure of HIV status focused on synthesizing global literature in terms of disclosure processes, reasons for disclosure and the impact of disclosure or non-disclosure on the wellbeing of children, parents and family. The results indicate that there is a low disclosure rate worldwide. According to the review, the parents' decision to disclose their HIV diagnosis to children is influenced by a variety of factors. These factors include: individual characteristics of parents and children, the health status of parents, parenting practices, family relationships, social norms and the children's cognitive developmental level (Qiao et al., 2013a). This study will focus on maternal characteristics and investigate which maternal socio-demographic variables are significantly associated with disclosure and non-disclosure. This research will also focus on maternal psychological functioning by comparing the two groups of mothers to identify whether they differ significantly in their experience of depression symptoms, coping styles and parenting stress.

In sub-Saharan Africa, a review conducted by Mkwanazi et al. (2012) focused on studies conducted specifically in sub-Saharan Africa. These studies show that mothers are willing to disclose their HIV status to their children of primary school-going age. However, for a number of reasons they do not feel adequately equipped to do so. Mothers feel unsure about the appropriate age at which disclosure should take place. They also do not feel confident to answer

questions about HIV by children and are concerned about the reactions of the children (Mkwanazi et al., 2012). In the sub-Saharan region the decision whether to disclose or not is most commonly linked to the child's age and gender as well as to the mother's stage of disease (Rochat et al., 2013). Mothers mostly perceive an older child as more mature and able to handle the mother's HIV diagnosis (Armistead, 2001; Tiendrebeogo et al., 2013). Disclosure is commonly linked to a child's gender, specifically a female child, because in the event of a mother's hospitalization, a girl child will most likely assume household responsibilities (Geiselhart et al., 2008). However, in some African societies this might not be the case because female children are consistently expected to assume household responsibilities regardless of the mother's health (Palin, Armistead, Clayton, Ketchen, Lindner, Kokot-Louw, & Pauw, 2009). The mother's stage of the disease is commonly linked to disclosure because mothers may need to disclose in case of hospitalisation. Furthermore, children inquire about their mother's deteriorating health (Mkwanazi et al., 2012). Mothers may also disclose because they need support in ART adherence (Chaudoir & Fisher, 2010). In a South African study by Madiba (2013) the results indicate that disclosure of HIV status to children occurs within a context influenced by death, dying and discrimination. Even though ART is widely available and accessible in the country, the fear of death and dying continues to influence disclosure to children. Previously mothers disclosed to prepare children for maternal death; now with the availability of ART mothers disclose for support in treatment adherence (Madiba, 2013). Thus, maternal health and HIV stigma in the community are important factors that influence a mother's decision to disclose her HIV status to her child or children.

Maternal disclosure of HIV status appears to be associated with benefits in mental health of both mother and child (Mkwanazi et al., 2012). Children benefit from disclosure as a result of improved custody planning and an increase in knowledge about HIV and AIDS following disclosure (Mkwanazi et al., 2012). Mothers experience psychological benefits from disclosure

in that they experience a sense of relief from no longer having to keep their HIV status a secret (Schrimshaw & Siegel, 2002). Disclosure also creates increased social support which in turn translates to decreased anxiety and depression (Armistead et al., 2001). Keeping secrets from children has an unfavourable impact on both the mother and child's psychological well-being, and secrets can, furthermore, destroy the family structure. Maternal HIV infection has an impact on the family and can be a contributing factor to family dysfunction and stress. When a stressor (such as an HIV diagnosis) is kept secret in the family, children often feel confused and anxious (Palin et al., 2009). Another benefit of disclosure is that the child or children concerned can communicate openly about HIV and concerns about the mother's health (Nam, Fielding, Avalos, Gaolathe, Dickinson, & Geissler, 2009).

It is not always the case that disclosure leads to positive benefits for women. The results of a study conducted in New York show that disclosure of maternal HIV status to children was not associated with improved psychological wellbeing of the mother (as assessed by depression symptoms). In addition, there was no increase in social support resources (Simoni, Davis, Drossman, & Weinberg, 2000). A small number of mothers regretted disclosing their HIV status to their children. Mothers expressed the main reason for regret as not having planned for the disclosure event. They disclosed to their children during an emotional time which led them to just blurting out their HIV status (Murphy, 2008). These factors reiterate the need for psychosocial support services to aid mothers in effectively disclosing their HIV status. The fact that psychological functioning is not always enhanced by disclosure accentuates the importance of this research because it addresses inconsistencies evident in previous research. This study will provide more information on the experience of maternal psychological functioning observed in the two categories of maternal HIV status disclosure in the South African context.

2.4.2 Reasons for and against maternal HIV disclosure

According to Murphy et al. (2011) most mothers choose not to tell their young children about their HIV status. It is assumed that non-disclosure negatively impacts the mother's psychological as well as physical wellbeing. It can result in problems including anxiety, depression and phobias (Murphy et al., 2011). A popular example is one whereby mothers who have not disclosed their HIV status to their children end up missing their medical appointments as well as not taking their medication effectively because they are afraid that their children are observing them and that the children might suspect that something is wrong (Crankshaw et al., 2014; Murphy et al., 2011). Research conducted in the sub-Saharan region indicates that mothers have expressed their discomfort in talking to their children about issues of sexuality, illness and death because talking about such issues is considered taboo in some cultures (Mkwanazi et al., 2012). Mothers do not want to disclose their HIV status because they fear secondary disclosure by the child. They are also apprehensive of the possibility that community members may discriminate against the child based on the mother's HIV status (Mkwanazi et al., 2012). Other practical reasons cited for non-disclosure include: mothers do not know how to disclose and are concerned that their children will ask how they got infected (Rwemisisi et al., 2008). Mothers have also cited emotional reasons for non-disclosure. They believed that their children were too young and that HIV status disclosure would be too much of an emotional burden on their children, who they believe deserve a care-free childhood (Schrimshaw & Siegel, 2002).

Similarly, there are various reasons why some mothers choose to disclose their HIV status. Practical reasons for disclosure include: mothers want to be honest with their children, they want to educate them about HIV and they want the children to learn about their HIV status from them and not from other people (Mkwanazi et al., 2012; Schrimshaw & Siegel, 2002). Mothers also cited the developmental level of their children, their own deteriorating health and

the need for custody planning and other arrangements for their children as reasons for disclosure (Mkwanazi et al., 2012; Rochat et al., 2014).

2.4.3 Outcomes relating to maternal HIV disclosure

The reactions of children to maternal HIV status disclosure can be classified as both short-term (initial reactions immediately following the disclosure) and long-term (how children adjust to disclosure over time). Across research studies the initial reactions by children can be classified as negative (Murphy, 2008). The reaction of the children displayed anxiety caused by concerns about the mother's health and life expectancy. The children also reacted in a manner that expressed psychological distress in response to the disclosure; however, such reactions were short-term. It was found that the concerns of children about the HIV status of their mothers abated over time. In instances wherein, the concerns of children prevailed it coincided with periods of maternal illness. Children may experience a period of distress immediately after disclosure, but the majority adjust well in the post-disclosure period (Murphy, 2008).

Hawk (2007) conducted a review of articles published between 1995 and 2007 which focused on the issue of maternal disclosure. The review focused on the rates and predictors of maternal disclosure, how mothers plan and execute disclosure and adjustment in families after disclosure. The results from the review indicated that there were differences between adolescents and young children in terms of adjustment to maternal disclosure of HIV status. Young children who were aware of the HIV status of their mothers did not exhibit long term adjustment problems. Maternal HIV becomes normalized in the family life especially if the mother's health remains good. Adolescent children may exhibit more short-term problematic behaviour than younger children. These post-disclosure reactions among adolescents may be explained by the adolescents' need and desire for autonomy (Hawk, 2007). Therefore, when mothers disclose to adolescents, the children show more problematic behaviour. However, this

problematic behaviour might be explained by what the adolescents are going through (which is their need for desire and autonomy). The problematic behaviour is not entirely because of maternal disclosure. The news about the mother's HIV status may contribute a small portion towards the problematic behaviour (Hawk, 2007).

A few studies conducted in South Africa investigated the topic of maternal HIV status disclosure and its relation to child functioning. A study conducted by Palin and colleagues (2009) focused on maternal disclosure of HIV status to uninfected children between 11 and 16 years in the South African context. The purpose of the said study was to provide descriptive information about HIV disclosure by mothers and whether variables in the family context interact with maternal HIV disclosure to affect child functioning. They found that 44% of mothers had disclosed their HIV status to their children (11-16 years). The children reacted in a manner that showed concern and sadness on learning their mother's HIV status. The results showed that disclosure to children significantly predicted externalized behaviour (such as aggression, delinquency, and hyperactivity) by the children whilst family variables (such as the parent-child relationship) also directly affected child functioning. The research also found that family variables such as parent-child relationships do not interact with maternal disclosure to affect child functioning (Palin et al., 2009). The limitation of the study is that the data is reported from the mothers' perspective.

Another study conducted in urban South Africa investigated the association between maternal HIV status disclosure and child psychological and behavioural outcomes (Sipsma et al., 2013). It was found that only a few mothers (7.4%) disclosed their HIV status to their young children (6-12 years). Mothers more readily disclosed their HIV status to their children when they started to show symptoms of illness (Sipsma et al., 2013). The results of the study indicate that it is not the mother's HIV status, but rather the fact that she is ill (for example, being hospitalised or showing symptoms of illness) that affects a young child's behaviour. Children

whose mothers disclosed their status had significantly better behaviour and adaptive functioning than children who had not been disclosed to (Sipsma et al., 2013).

The Amagugu intervention implemented among Zulu families in rural South Africa (Rochat, Arteche, Stein, Mitchell, & Bland, 2015) aimed to optimize maternal HIV status disclosure. The intervention was divided into two stages. The first stage was a pre-disclosure stage whereby the counsellor worked with the mother to prepare and train her for the disclosure event. The post-disclosure stage involved sessions where the mother was counselled on health promotion and custody planning (Rochat et al., 2014). The project was evaluated by assessing the level of maternal disclosure and the effects of disclosure on the psychological outcomes of a sample of 281 mothers and their young uninfected children aged 6 to 11. At baseline only 9% of mothers reported disclosing their HIV status. An analysis after the intervention indicated that all mothers had disclosed their HIV status, some mothers disclosed fully and others partially disclosed their HIV status. Mothers who fully disclosed reported that their children reacted in an emotional manner and were surprised by the news (Rochat et al., 2014). The children's behaviours as assessed by the Child Behavior Checklist (CBCL) showed improvement after maternal disclosure of HIV status. There was a significant decrease in the internalizing and externalizing subscales of the CBCL, with a moderate to large effect size observed. This result is consistent with the existing literature from developed countries (Rochat et al., 2014). These findings indicate that planned maternal HIV status disclosure can have a positive effect on children's psychological functioning and behaviour.

Most research on maternal HIV disclosure in South Africa, as reviewed above, has focused on the child characteristics and the effects of disclosure on child outcomes (Rochat et al., 2013; Rochat et al., 2014; Sipsma et al., 2013). Previous research contributed to a sound understanding of factors that influence maternal HIV disclosure and how children react to their mothers' HIV status. However, there is a gap in research in terms of understanding maternal

characteristics and mental health in the context of maternal disclosure. The question is whether mothers experience different levels of psychological wellbeing after disclosure to their young children. The research will specifically focus on whether mothers experience significant differences in psychological variables such as depression symptoms, coping style and parenting stress. In the next section, literature on depression symptoms, parenting stress and coping strategies in the context of maternal disclosure, is discussed.

2.5 Depression symptoms and maternal HIV status disclosure.

The prevalence rate of depression symptoms is higher among the population living with HIV than in the general population in Sub-Saharan Africa (Seth et al., 2014). This notion is based on early research which showed that mothers living with HIV are more likely to be diagnosed with clinical depression (Johnson & Lobo, 2001). It is estimated that depression symptoms are prevalent in 2% to 56 % of the population living with HIV (Seth et al., 2014). Depression symptoms among women living with HIV have been associated with poorer ART adherence, rapid disease progression and a higher likelihood of AIDS-related mortality (Cook et al., 2014). The availability and accessibility of ART among individuals living with HIV has paved a way for HIV to become a manageable chronic disease. It is now essential for health care providers to be aware of and address the psychological issues associated with HIV among infected and affected families (Seth et al., 2014).

Women living with HIV face various difficulties and are at an increased risk of experiencing psychological distress symptoms (Kotze et al.,2013). The distress is often related to cultural demands to care for a spouse and children as well as a lack of support from family and friends while they experience deteriorating health as a result of self-neglect (Mahajan et al., 2008; Medley et al., 2004; Susser, 2011). It is essential to investigate how women experience depression symptoms after disclosure to their young uninfected children in order to assist them to manage their mental health issues amidst various unique stressors (Delaney, Serovich, &

Lim, 2009). Thus, the researcher will investigate whether mothers who disclosed differ in their experience of depression symptoms as opposed to those who did not disclose.

Delaney et al. (2009) investigated whether there were differences in the psychological wellbeing (as assessed by depression, anxiety and stress) of mothers who disclosed to all, some or none of their children using an American sample. The results showed no significant differences in the depression symptoms of mothers who disclosed to their children and those who did not disclose. The aforesaid study reported no differences in depression symptoms related to disclosure of maternal HIV status to children (Delaney et al., 2009). On the contrary, research conducted earlier (Wiener, Battles, & Heilman, 1998) reported that mothers who disclosed their HIV status to their children presented significantly lower levels of depression symptoms than mothers who had not disclosed. Research conducted in sub-Saharan Africa (Mkwanazi et al., 2012; Obermeyer et al., 2011; Wiener et al., 2007) confirmed the latter. This research indicated that after disclosure mothers experienced reduced symptoms of depression and anxiety. Taking this into account the current research sets out to determine with the use of a South African sample, if there are significant differences in depression symptoms between the two groups of mothers (mothers who disclosed as opposed to those who do not disclose). It is possible that mothers who disclosed to their children experienced less depression symptoms (i.e. fewer depression symptoms). In this research the two groups of mothers will be compared in terms of their experience of depression symptoms. The researcher will investigate if disclosing and non-disclosing mothers differ significantly in their depression scores at baseline.

2.6 The mother-child relationship and HIV disclosure.

An HIV diagnosis confronts a person with several challenges such as the physical challenges of a chronic disease and the impact of the stigma associated with HIV. Mothers living with HIV must also meet the demands of child-rearing and deal with the negative impact of their

illness upon their families (Murphy, 2008). The researcher will focus on the mother-child relationship (assessed on parenting stress) as one of the variables in the study. Family relationships are particularly important because, as indicated earlier, the fluctuating health status of mothers living with HIV necessitates that they receive considerable support in respect of child-rearing (Murphy, 2008). As mentioned earlier, an HIV-positive diagnosis does not only affect mothers as individuals, but also affects the way they care for their families (Murphy, 2008).

Families affected by HIV in developing countries are at a greater risk of psychosocial problems than non-affected families. Based on a South African sample, Lachman, Cluver, Boyes, Kuo, and Casale (2014) found that positive parenting was less likely in families affected by HIV and AIDS, as opposed to non-affected families (Lachman et al., 2014). This has been confirmed by research elsewhere (Murphy, Marelich, Herbeck, & Payne, 2009; Murphy, Armistead, Marelich, & Herbeck, 2015). Mothers living with HIV reported less monitoring of their children's behaviour, compared to uninfected mothers. Poor physical health and the effect of HIV on the mental health of the mothers have been identified as factors contributing to compromised parenting (Murphy et al., 2009). Parenting stress can directly and indirectly affect parenting behaviour. Research results confirmed that parents with poor health reported higher levels of parenting stress than healthy parents (Murphy et al., 2010; Rochat et al., 2015). A meta-analysis by Tenzek, Herrman, May, Feinerd, and Allenb (2013) conducted to examine the impact of the decisions by mothers to disclose their HIV status to their children, found evidence that maternal disclosure of HIV status might strengthen parent–child relationships and improve family cohesion (Tenzek et al., 2013). The same results have been found in earlier research. Women who had discussed their HIV status with their immediate families reported stronger family cohesion than mothers who had not disclosed (Schrimshaw & Siegel, 2002). This suggests that disclosure may be used as a method to strengthen family relations and

alleviate tension experienced in HIV affected families. Rochat et al. (2015) investigated parenting stress during the Amagugu intervention study. The results indicate a significant reduction in parenting stress scores using two subscales of the Parenting Stress Index (Parental Distress and Parent-Child Interaction subscales) after disclosure. However, there is limited research that directly links parenting stress and maternal disclosure. In this study, the researcher will investigate whether there are differences in parenting stress scores between disclosing and non-disclosing mothers. In view of the literature, the expectation is that non-disclosing mothers may experience more parenting stress than disclosing mothers. In this study the two groups of mothers will be compared to distinguish whether they differ significantly in their parenting stress scores for the two subscales of the parenting stress index (Parental Distress and Parent-Child Interaction subscales).

2.7 Coping and maternal HIV status disclosure

Mothers living with HIV reported that their greatest source of stress was combining maternal, medical and psychological demands with the demands of coping with a chronic illness (Murphy et al., 2015). It is important for mothers to find effective coping strategies in order to deal with their HIV diagnosis and thus reduce psychological distress (Hough, Brumitt, Templin, Saltz, & Mood, 2003). Active coping style is associated with positive health and psychosocial outcomes in people living with HIV, while avoidant coping style is associated with negative health and psychosocial outcomes (Chida & Vedhara, 2009). Disclosure of one's HIV status is often seen as the first step in the coping process (Medley, Kennedy, Lunyolo, & Sweat, 2009). Previous research (Simoni et al., 2000) shows that active coping strategies have been associated with HIV status disclosure. They found that disclosure rates were positively associated with the use of more adaptive coping strategies (such as spiritual resilience, constructive cognitions, and community involvement). In contrast, Kotze et al. (2013) using a South African sample, investigated which psychosocial variables are associated with coping

strategies of mothers living with HIV diagnosed during pregnancy. The results showed no association between coping style and disclosure of HIV status. In this study disclosing and non-disclosing mothers will be compared in terms of coping style and coping strategies. It is anticipated that disclosing mothers may engage in more active coping strategies as a means of dealing with their HIV diagnosis than non-disclosing mothers. In this study the researcher is going to compare whether disclosing and non -disclosing mothers differ significantly in active coping style, avoidant coping style and individual coping strategies.

2.8 Theoretical framework

Currently, there is no theoretical framework that can explain maternal HIV disclosure. Past empirical studies have not been conducted against a theoretical framework of HIV parental disclosure (Qiao, Li, & Stanton, 2013b). Two main theoretical frameworks are used to understand HIV status disclosure in general. The first framework is the disease progression theory. According to this perspective, individuals living with HIV will disclose their HIV status as a result of disease progression. Therefore, as people living with HIV become ill, they are more likely to disclose their HIV status because they can no longer keep their illness a secret. Another key to the time of disclosure is when they commence with ART. The behavioural changes required for adherence to ART make it difficult to keep the illness a secret (Serovich, 2001). The availability of ART limits disease progression and the appearance of symptoms. This theory may therefore not be so appropriate to motivate disclosure in the current context.

The second framework is the consequence theory. This perspective proposes that disclosure occurs after the person living with HIV has gone through a process of careful consideration of the consequences of disclosing their HIV status. The person will weigh up the positive and negative consequences of disclosing his or her status (Serovich, 2001). This theory is limited in that disclosure is viewed as a single event (Chaudoir & Fisher, 2010) and it does not take

into consideration the context and social system of the people engaging in HIV status disclosure (Qiao et al., 2013b).

In this research the socio-ecological approach (Bronfenbrenner, 1977; McLeroy, Bibeau, Steckler, & Glanz, 1988) is chosen as a theoretical framework to understand the dilemma mothers face with regards to HIV status disclosure to their young uninfected children. This framework proposes that various factors on different levels play a role in the decision to disclose one's HIV status. Both internal and external factors should be incorporated as part of an approach to understand people's health behaviour. Therefore, individual-focused and environment-focused strategies can both be employed as part of health behaviour change (Linke, Robinson, & Pekmezi, 2013). In order to understand the socio-ecological approach to health behaviour one must understand its four fundamental principles:

1. External factors in the environment (e.g. stigma) and internal factors (e.g. depression) in the individual which may influence health behaviour interaction in a dynamic way.
2. People are embedded in a complex and multidimensional environment that influences behaviour.
3. Interventions that target health behaviour should consider both the individual (e.g. person living with HIV) and people (e.g. family and community) who are embedded in a complex and multidimensional environment.
4. There are multiple levels of influence which are exerted by the people-environment interaction. For example, individuals may modify their settings and in turn the settings may influence the individual (Linke et al., 2013).

The socio-ecological approach is employed in this research because it recognises that an individual exists in larger social systems and thus incorporates the broader contexts that affect health behaviour. For example, the approach takes into consideration how relationships in

family can affect a person's health (Linke et al., 2013; Qiao et al., 2015). In addition, the approach emphasizes the interaction between individual and environmental level factors that underlie health behaviour (Qiao et al., 2015). The socio-ecological approach allows interventions to target health behaviour at various levels of influence such as intrapersonal, interpersonal, organisational, community and public policy. This approach also recognises that factors at various levels are interactive and reinforcing (Linke et al., 2013; Qiao et al., 2015). The socio-ecological approach in this study will be employed to understand maternal disclosure of HIV status to their young children. For the purposes of this research the focus will be on variables that are related to maternal HIV disclosure at intrapersonal (e.g. depression symptoms) and interpersonal level (e.g. mother-child relationship as assessed by parenting stress) with due regard to the possible influence of broader social variables. The socio-ecological approach can help the researcher understand the dilemma of maternal HIV status disclosure.

2.9 Conclusion

In summary, women's socio-demographic characteristics in the sub-Saharan region have been studied in the context of HIV status disclosure to partners. This study seeks to investigate the association of maternal socio-demographic characteristics in the context of maternal HIV status disclosure to young uninfected children. Maternal disclosure has been studied from various perspectives: the characteristics of mothers and children, the reaction of the child and factors that influence HIV status disclosure. Findings across literature of previous research indicate that the age and gender of the children are consistent important factors that influence maternal HIV status disclosure. Children's initial reactions to their mother's HIV status are negative but over time their reactions become positive. HIV status disclosure is beneficial to the mental health of the mother, provided that there is adequate social support in place. Disclosure of HIV status may lead to social support from family towards the mothers resulting

in reduced depression symptoms due to the relief experienced of not having to keep their HIV status a secret any more.

There is a gap in the research to identify whether disclosing and non-disclosing mothers differ significantly in their experience of psychological variables (depression symptoms, coping style and parental stress) after disclosure. In order to understand the dilemma mothers face with regards to HIV disclosure, the socio-ecological approach will be used as a theoretical framework to guide the study. The research methodology utilised to investigate differences between disclosing and non-disclosing mothers will be addressed in the next chapter.

3. CHAPTER 3: RESEARCH METHODOLOGY

3.1. Introduction

This study entails a secondary analysis of the baseline data of the Kgolo Mmogo project. The Kgolo Mmogo project was a randomised controlled trail conducted in Tshwane (Eloff et al., 2014). The aim of the project was to investigate the effect of maternal HIV on the well-being of young uninfected children between the ages of 6 and 10 (Sipsma et al., 2013) as well as the effect of a resilience intervention on the well-being of these children (Eloff et al., 2014). In the Kgolo Mmogo project, mothers living with HIV were recruited from clinics in Tshwane. Data was collected by research assistants through one on one interviews with mothers living with HIV. These interviews were conducted at the clinics where the women received treatment. Research assistants were trained to complete the questionnaires with the participants in their vernacular. All mothers signed the consent form before they were interviewed and entered into the study (Eloff et al., 2014). In the data collection process data was obtained on the psychological well-being of mothers, the mother-child relationship as well as the development and adjustment of the children at baseline and post intervention.

One of the questions asked in the Kgolo Mmogo project was whether mothers had disclosed their HIV status to their young uninfected children. In this study a quantitative approached is used to describe socio-demographic variables and investigate if there is a significant association between those variables and maternal HIV status disclosure. A quantitative approach is also used to compare significant differences in the experience of psychological variables of mothers who have disclosed their status to their young children as opposed to those who did not. This study will use the data collected at baseline as this data has not been analyzed.

3.2. Research design

A comparative descriptive approach was used to investigate differences between the two groups of mothers to obtain a better understanding of maternal HIV status disclosure to young

uninfected children in the South African context. A comparative descriptive approach involves describing the specific differences between two or more groups as they occur in the environment without introducing manipulation (Creswell, 2013; Mitchell & Jolley, 2012; Sousa, Driessnack, & Mendes, 2007; Taylor, Kermode, & Roberts, 2006). The comparative descriptive research design is similar to a simple descriptive research design; however, the former design has an added advantage in that it allows for comparisons of groups (Taylor et al., 2006). This study will investigate the differences in depression symptoms, coping style and parenting stress present in mothers who have disclosed and mothers who have not disclosed their HIV status to their children.

The following hypotheses were investigated based on previous literature:

1. H_0: There are no significant differences in depression symptoms between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children.

   H_1: There are significant differences in depression symptoms between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children.

2. H_0: There are no significant differences in coping style between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children.

   H_1: There are significant differences in coping style between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children.

3. H_0: There are no significant differences in parenting stress scores between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children.

H_1: There are significant differences in parenting stress scores between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children.

The secondary aim of the study is to explore which socio-demographic characteristics (mother's age, employment status, marital status and level of education) are significantly associated with maternal HIV status disclosure to young uninfected children.

3.3 Sampling

Cross-sectional data from the baseline assessment of the Kgolo Mmogo project was used for this study. The Kgolo Mmogo project used purposive sampling. Mothers living with HIV attending local clinics were approached to participate in the research. The eligibility criteria included being a primary caregiver of a young uninfected child (6-10 years), being in the possession of a positive HIV test document and speaking one of the four local languages (Sepedi, Sesotho, Setswana and isiZulu). Participants were excluded from the study if the child was living with HIV or if there was a family member in the household other than the mother with a serious illness that could influence the relationships in the household (Sipsma et al., 2013). The Kgolo Mmogo dataset had a total of 406 mothers that were living with HIV.

In this study, the sample consisted of 406 mothers living with HIV who answered the question on HIV status disclosure to their young children: *What did you tell your child about your HIV status?* Out of the 406 mothers 87.7% indicated that they did not disclose (*I have not told my child anything about my health*), 7.1% indicated full disclosure (*I have told my child I have HIV/AIDS*) and 4.5 % indicated partial disclosure (*I have told my child I have a serious health/medical condition or I have told my child that I have something wrong*) (See Table 1).

Table 1. Maternal HIV status disclosure in the Kgolo Mmogo project

Type of HIV status disclosure	Frequency	%
No disclosure: *I have not told my child anything about my health*	356	87.7
Partial disclosure: *I have told my child that I have something wrong*	8	2
Partial disclosure: *I have told my child I have a serious health/medical condition*	10	2.5
Full disclosure: *I have told my child I have HIV/AIDS*	29	7.1
Secondary disclosure: *Someone else told my child that I have HIV/AIDS*	3	0.7
Total	406	100

In order to investigate if there were any differences in psychological variables (depression symptoms, coping style and parenting stress) of mothers who have disclosed and those who have not disclosed, the researcher decided to group mothers who have disclosed n=47 (adding mothers who fully disclosed and those who partially disclosed) and those who have not disclosed n= 356 ex post facto. Due to the differences in numbers between the two groups, the researcher used SPSS (random selection of cases) to obtain a random sample from the non-disclosing group to include in the research. This enabled the researcher to have equal numbers of disclosing and non-disclosing mothers. The advantage of having equal numbers for comparisons eliminates the possibility of the results being attributed to extraneous variables which might be found in a larger sample. The researcher considered using a matching pairs approach to select mothers in the non-disclosing group, however, decided against it for critical reasons. Firstly, the matching pairs approach requires that the participants be matched on all variables except the ones under investigation (Gravetter, & Forzano, 2012). This would complicate the current study as it would require matching for most of the maternal socio-

demographic variables when maternal psychological variables are under investigation (i.e. mothers be matched according to their age when there is an investigated about their depression scores). Secondly, the matching pairs approach would interfere with the secondary aim of this study. The researcher decided to use random sampling so that all mothers in the non-disclosing group have an equal chance of being selected. The sample achieved for the current study was N = 97 with the disclosing group consisting of 47 mothers and a random sample of 50 mothers from the non-disclosing group. This sample was used in the analysis of data for both the primary and secondary research aim (See Table 2).

Table 2. Sample achieved for the current research

Groups of mothers by HIV status disclosure	Frequency	%
No disclosure	50	51.5
Disclosure	47	48.5
Total	97	100

3.4 Measurement instruments

The measuring instruments used in the Kgolo Mmogo research were developed in English and validated in western populations. In order to make these instruments relevant to the South African context, cultural modifications were made through a process of consultation with local personnel before translating the instruments and then translating them back into the original language. In addition, a pilot study was conducted with 22 mothers living with HIV to test their level of understanding and cultural appropriateness of the questions. The subsequent modifications of the instruments were of a minor nature and included changes like substituting

words that were not clearly understood with more colloquial terms that provided more clarity (Eloff et al., 2014). The instruments that were used in the current study are described below.

3.4.1 Centre for Epidemiological Studies-Depression scale (CES-D).

The depression symptoms of mothers living with HIV were assessed by the CES-D. This scale is a widely used self-reporting instrument for assessing depression symptoms (Radloff, 1977). The scale consists of 20 items that cover the affective, psychological and somatic symptoms of depression. Participants were asked to rate the frequency of their feelings over the preceding 7 days using a 4-point Likert scale ranging from "rarely or none of the time" to "most or all of the time". Scores range from 0 to 60, with a score of 16 or above indicating significant depressive symptomatology (Radloff, 1977). The CES-D has been validated and can be used to determine levels of depression symptoms in both the primary health care and clinical settings (Husaini, Neff, Harrington, Hughes, & Stone, 1980). Previous research among cancer patients has validated the CES-D as a reliable instrument for assessing depression symptoms (Hann, Winter, & Jacobsen, 1999). The CES-D had a Cronbach alpha of 0.88 in a study of Myer et al. (2008). The CES-D has been validated across race groups in the South African population (Pretorius, 1991).

Symptoms of depression are common in people living with HIV. The CES-D has been criticized for a potential methodologic weakness when assessing depression symptoms in the population living with HIV. Some critics have noted that the somatic symptoms of depression measured by the CES-D can be confused with symptoms of HIV infection and disease progression. This might inflate depression scores in people living with HIV (Cook et al., 2002; Kalichman, Rompa, & Cage, 2000). In order to deal with this potential weakness, the researcher decided to remove the 5 items that assess somatic symptoms of depression in the CES-D scale (items that assess fatigue, insomnia, apathy, difficulty in concentrating, and weight or appetite loss). This has also been done in previous studies and resulted in scores ranging from 0 to 45,

high scores (16 and above) indicating the presence of depression symptoms (Eloff et al., 2014). In a South African study using the data of 293 women living with HIV, Makin et al. (2008) assessed the reliability of this measure and obtained a Cronbach alpha of 0.88 on the CES-D. In the current research the adapted CES-D scale has good reliability, with a Cronbach Alpha coefficient of α = 0 .89. A Cronbach alpha of above 0.80 is considered acceptable for a psychometric measure.

3.4.2 Brief COPE

The coping strategies of mothers living with HIV were assessed using the Brief COPE scale in the Kgolo Mmogo project. Brief COPE is a self-reporting instrument which is an abbreviated version of the full COPE inventory (Carver, 1997). The scale has 14 subscales each consisting of 2 items which measure the following coping strategies: *self-distraction, denial, active coping, substance use, behavioural disengagement, venting, planning, humour, positive framing, acceptance, religion, use of emotional support, use of instrumental support* and *self-blame* (Carver, 1997). These coping strategies can be grouped together in two sub-scales namely active and avoidant coping (Smith et al., 2001). The participants were asked to indicate how often they use a coping strategy to deal with stressors. Responses were provided on a 4-point Likert response scale ranging from "not at all" to "a lot of the time". In the research of Makin et al. (2008) with women living with HIV she obtained a Cronbach alpha of 0.75 for positive coping and 0.54 for avoidant coping. In the Kgolo Mmogo study the subscale active coping had a Cronbach alpha of α = 0.73 and avoidant coping α = 0.70 (Boeving-Allen et al., 2014).

In the current study the researcher grouped the following coping strategies: *active coping, planning, humour, positive framing, acceptance, religion, use of emotional support,* and *use of instrumental support* into Active coping style and the remaining strategies were grouped into Avoidant coping style (*self-distraction, denial, substance use, behavioural disengagement,*

self-blame, and venting). The reliability for the Active coping style was acceptable with a Cronbach Alpha coefficient of 0.78 (N = 97). The Avoidant coping style had lower reliability with Cronbach Alpha coefficient (α = 0.64).

3.4.3 Parenting Stress Index (PSI)

The mother and child relationship was assessed using the PSI short form, a self-report measure assessing stress. The PSI is able to identify dysfunctional parenting and can predict the potential for parental problems and child adjustment difficulties within the family system (Abidin, 1990). The PSI Short form (PSI-SF) consists of 36 items. Participants respond on a five-point Likert scale which ranges from 1 = strongly agree to 5 = strongly disagree with high scores indicate parenting stress (Boeving-Allen et al., 2014). The PSI has been normed on more than 2,500 parents and is useful to identify and prevent family problems (Abidin, 1990). The scale has been validated among Chinese mothers in Hong Kong and it was found to have a reliability coefficient of 0.93 (Tam, Chan & Wong, 1994).

In the Kgolo Mmogo project parenting stress was assessed using two subscales of the PSI, namely Parenting Distress and Parent-Child Dysfunction. In studies by Boeving-Allen et al. (2014) and Eloff et al. (2014), utilising the Kgolo Mmogo data, the two subscales obtained high reliability coefficients: Parenting Distress (α = 0.82) and Parent-Child Dysfunction (α = 0.82).

In the current study parenting stress was assessed using the two subscales of the PSI. The first subscale Parenting Distress (11 items) measures the mother's perception of own behaviour such as perceived competence, marital conflict, views of social support and life restrictions due to parenting demands (e.g. *I find myself giving up more of my life to meet my child's needs than I ever expected*). The second subscale Parent-Child Dysfunction (12 items) measures the mother's views and expectations of the child (e.g. *my child rarely does things that make me feel good*). The PSI subscales showed good reliability. The Parenting Distress had a Cronbach

Alpha coefficient of ($\alpha = 0.83$) while the Parent-Child Dysfunction had a Cronbach Alpha coefficient of ($\alpha = 0.81$).

3.4.4 Socio-demographic variables

Self-report measures were used in the Kgolo Mmogo questionnaire to gather information on socio-demographic factors of the mothers. These variables (maternal age, employment status, marital status and level of education,) are assessed through descriptive statistics (see Appendix C).

3.5 Data analysis

Quantitative data analysis for this study was conducted using the Statistical Package for the Social Sciences (SPSS) version 23®. Preliminary descriptive analysis was conducted in the two groups of mothers (disclosed and non-disclosing mothers). In general, descriptive analysis involves describing basic features of data and measurement in order to summarise data of a sample in a meaningful way (Gravetter & Forzano, 2012). In this study descriptive analysis was carried out by measures of central tendency (mean, median, and mode), and measures of spread (standard deviation). The researcher used cross tabulations and custom tables to describe socio-demographic variables in the two groups of mothers. In order to test for significant relationships between maternal HIV status disclosure and socio-demographic variables in the two groups the Chi-square test for independence was conducted. This type of test is used to explore the relationship between two categorical variables; i.e. the variables can have two or more categories. This test compares the observed frequencies of cases that occur in each category (Pallant, 2010). One requirement is that the lowest expected frequency in any cell should be 5 or more (Pallant, 2010).

This study used non-parametric statistics, specifically the Mann-Whitney U test, to compare the two groups of mothers for significant differences. According to Pallant (2010) non-parametric statistics do not make assumptions about the underlying population distribution.

These techniques are not restricted by the same assumptions that need to be taken into consideration in parametric statistics. The disadvantage of non-parametric statistics is that the techniques are less sensitive and as a result may lead to failure to reject the null hypothesis when it is not true; therefore, accepting that there are no differences between two groups when differences actually exist (Pallant, 2010). The advantages of non-parametric statistics are ideal when one has data that is measured on the nominal and ordinal scales. It is also appropriate when the sample sizes are small and when the data does not meet the requirements for parametric statistics. There are two assumptions one has to consider when conducting non-parametric techniques. The first assumption is random samples and the second is independent observations (Pallant, 2010).

The Mann-Whitney U test is a nonparametric test, and is used when the assumptions of equal variances between groups are not met. The Mann-Whitney U test is regarded as a non-parametric alternative to the t-test for independent samples (Pallant, 2010). The test was used to assess for significant differences in depression symptoms, coping style and parenting stress of mothers who have disclosed and mothers who have not disclosed their HIV status. The Mann-Whitney U test changes the scores of the continuous variable to rank scores across the two groups. This test then evaluates whether the ranks for the two groups differ significantly. As a result of the scores being converted to ranks, the actual distribution of the ranks does not matter. Over and above that, this technique compares medians and not means (Pallant, 2010). Analyzing the differences between the two groups enables the researcher to compare the psychological variables present in each group. All missing data was excluded from the analysis.

3.6 Ethical considerations

The Kgolo Mmogo project was ethically approved by the institutional review boards of the Medical Faculty of the University of Pretoria as well as Yale University. Mothers who participated in the original research gave informed consent which also included that

participants consented to their data being archived and used for further analysis. A team of researchers participated in the Kgolo Mmogo project and contributed to the data analysis. The project leaders of the Kgolo Mmogo research gave the researcher permission to access and analyse the data.

The current research, which is a secondary analysis of the Kgolo Mmogo database, was ethically approved by the institutional review board of the Faculty of Humanities of the University of Pretoria. In this study the researcher did not have any direct contact with the original participants of the research. Confidentiality and anonymity of the participants were maintained as there is no identifying information such as names, home addresses and contact details in the data base.

3.7 Conclusion

In chapter 3 the details of the quantitative approach employed to investigate the hypotheses were discussed as well as the method of data collection in the Kgolo Mmogo project. The sampling process, research instruments and data analysis used in this study were explained. Chapter 4 will detail the results of descriptive and inferential statistics performed to compare the two groups of mothers.

CHAPTER 4: RESULTS

4.1 Introduction

In this chapter the findings of statistical analyses conducted on maternal socio-demographic variables and psychological variables will be presented. The cross-sectional data of the Kgolo Mmogo project collected at baseline was used in this research. Mothers were divided into two groups (disclosure and no disclosure) according to their indication of maternal HIV status disclosure to their young uninfected children. In this chapter descriptive results for the overall sample and descriptive results within the two groups of mothers will be presented first. Secondly, there are also detailed findings with regards to significant associations between maternal HIV status disclosure to young uninfected children and the following socio-demographic factors: mother's age, employment status, marital status and level of education. The last part of the results focuses on comparing the two groups of mothers in terms of their experience of the following psychological variables: depression symptoms, coping style and parenting stress scores.

4.2 Demographic information

The cross-sectional data of the Kgolo Mmogo project was collected in two township communities in Tshwane, South Africa. Mothers living with HIV were recruited from local primary health clinics and immunology clinics (Boeving-Allen et al., 2014). The overall sample achieved for this study is N = 97, with n = 47 mothers in the disclosed group and n = 50 mothers in the non-disclosing group. In this section a description of the sample of mothers in this study will be given.

4.2.1 Maternal age

Mothers indicated their age in years. The youngest mother was 22 while the oldest was 52. The mean age was M = 33 (*SD* = 6.34) (see Table 3 for this and similar instances).

4.2.2 Mothers' employment status

With regards to employment status, 54.6% of mothers indicated that they were unemployed and looking for work, while 12.4% indicated that they were unemployed but not looking for work. Employed status for mothers was 30.9%, with 7.2% of mothers indicating full-time employment, 17.5% indicated part-time employment and 6.2% identified as self-employed (which included informal work such as selling goods.) Only 2.1% indicated their employment status as "other", which could refer to mothers who might be in school or doing volunteer work (see Table 3).

4.2.3 Mothers' marital status

When looking at marital status the results show that 14.4% of the mothers were married, this included common law marriages. The majority of mothers (58.8%) were not married but had a partner, whereas 22.7% of mothers indicated that they were single with no partner. Only 4.1% of mothers indicated that they were widowed (see Table 3).

4.2.4 Mothers' level of education

The researcher grouped the level of education into different categories. The categories are mutually exclusive and exhaustive, which means that one participant cannot belong to two groups. The first category is that of no schooling. In this category mothers have no formal education. The primary school category consists of all mothers who have completed any grade from Grade 1 up to Grade 7 as their highest qualification. The high school category consists of mothers who have completed any grade from 8 up to 11 as their highest qualification. The last two categories were made up of mothers who completed their matric (Grade 12) and those who

had some sort of tertiary education (formal education after completing Grade 12). The results indicated that the majority of mothers (52.1%) had some high school education, while 24% had a Grade 12 whereas only 3% of mothers had some tertiary education. Lastly, 19.8% of the mothers only completed primary school and 1% of the mothers reported having no schooling (see Table 3).

Table 3: Summary of descriptive statistics

Section 4.2.1: Descriptive statistics for age

	N statistic	Minimum statistic	Maximum statistic	Mean statistic	Std. Deviation
Age	97	22	52	33.09	6.339

Section 4.2.2: Descriptive statistics of employment status in overall sample

Employment status	Frequency	%
Working full-time	7	7.2
Working part-time	17	17.5
Self-employed (including informal work such as selling goods)	6	6.2
Unemployed - looking for work	53	54.6
Unemployed - not looking for work	12	12.4
Other	2	2.1
Total	97	100

Section 4.2.3: Descriptive statistics of marital status in overall sample

Marital status	Frequency	%
Single with no partner	22	22.7
Not married but have a partner	57	58.8
Married/common law marriage	14	14.4
Widowed	4	4.1
Total	97	100

Section 4.2.4: Descriptive statistics of level of education in overall sample

Level of education category	Frequency	%
No schooling	1	1.0
Primary schooling	19	19.8
High school	50	52.1
Grade 12/Matric	23	24.0
Tertiary	3	3.1
Total	96	100

Note: missing n =1

4.3 Descriptive statistics and demographic variables

Cross tabulations were conducted using SPSS version 23® to analyse the socio-demographic variables of the two groups of mothers. In each section, the researcher will refer to the results for the overall sample, as well as those for the non-disclosing and the disclosing mothers. In addition, significant relationships between maternal HIV status disclosure and the chosen socio-demographic variables will be given.

4.3.1 Age and maternal HIV status disclosure

Mothers' ages were grouped into categories using SPSS version 23®; the groupings for the age categories are based on the distribution of data on the maternal age variable. The age categories are as follows: category one is mothers who are ≤30 years old, the second category is made up of mothers aged 31-35 years and the last age category is for mothers aged 36 years and older.

The results indicate that within the no disclosure group (n = 50) 46% of mothers fall in the ≤30 years category, 26% in the 31-35 age category and 28% in the ≥36 age category. The results indicate that within the disclosure group (n = 47) 38.3% of mothers fall in the ≤30 years category, 25.5 % in the 31-35 age category and 36.2% in the ≥36 age category (see Figure 4.3.1).

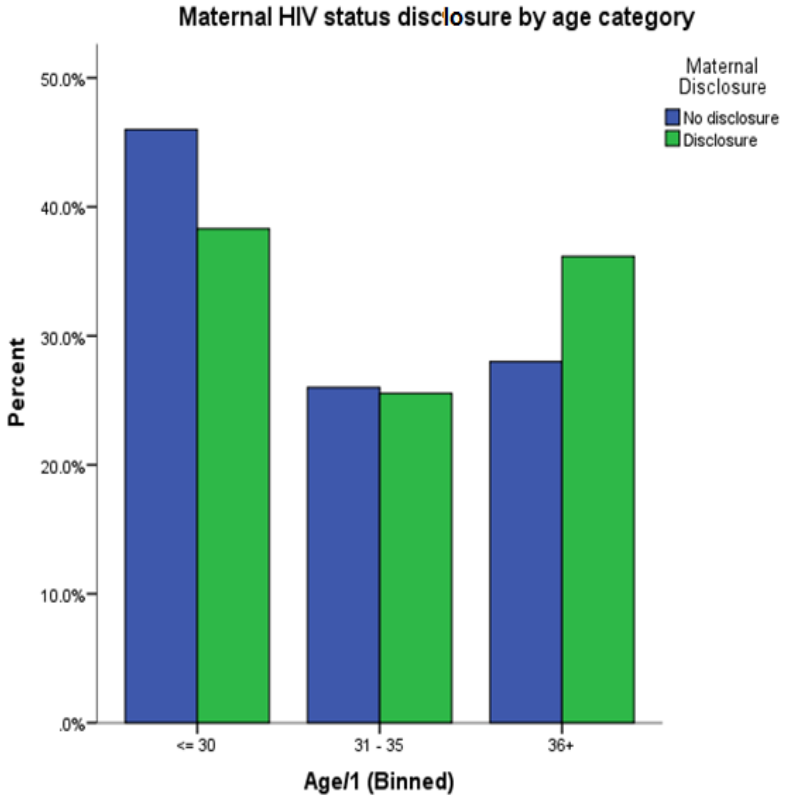

Figure 4.3.1: Clustered bar graph (% of number of cases) of maternal disclosure and age category.

Figure 4.3.1 indicates that in the ≤30 years age category, there are slightly more mothers who did not disclose while slightly more mothers disclosed in the ≥36 age category. To explore whether there is a statistically significant association between maternal age and HIV disclosure status, a Chi-squared test for independence was performed. The Chi-square test (with Pearson Chi-square) indicated no significant association between maternal disclosure and age category, χ^2 (1, n = 97) = 0.85, p = 0.654, Cramer's V = 0 .094. In the overall sample (N = 97) the results revealed that there was no significant relationship between maternal HIV status disclosure and age category.

4.3.2 Employment status and maternal HIV status disclosure

In the non-disclosure group (n = 50) results indicated that 36% of mothers were employed, while the majority of mothers (64%) were unemployed. The disclosing group's (n = 47) results indicate that 25.6% of mothers were employed, while the majority (70.2%) were unemployed (see Figure 4.3.2).

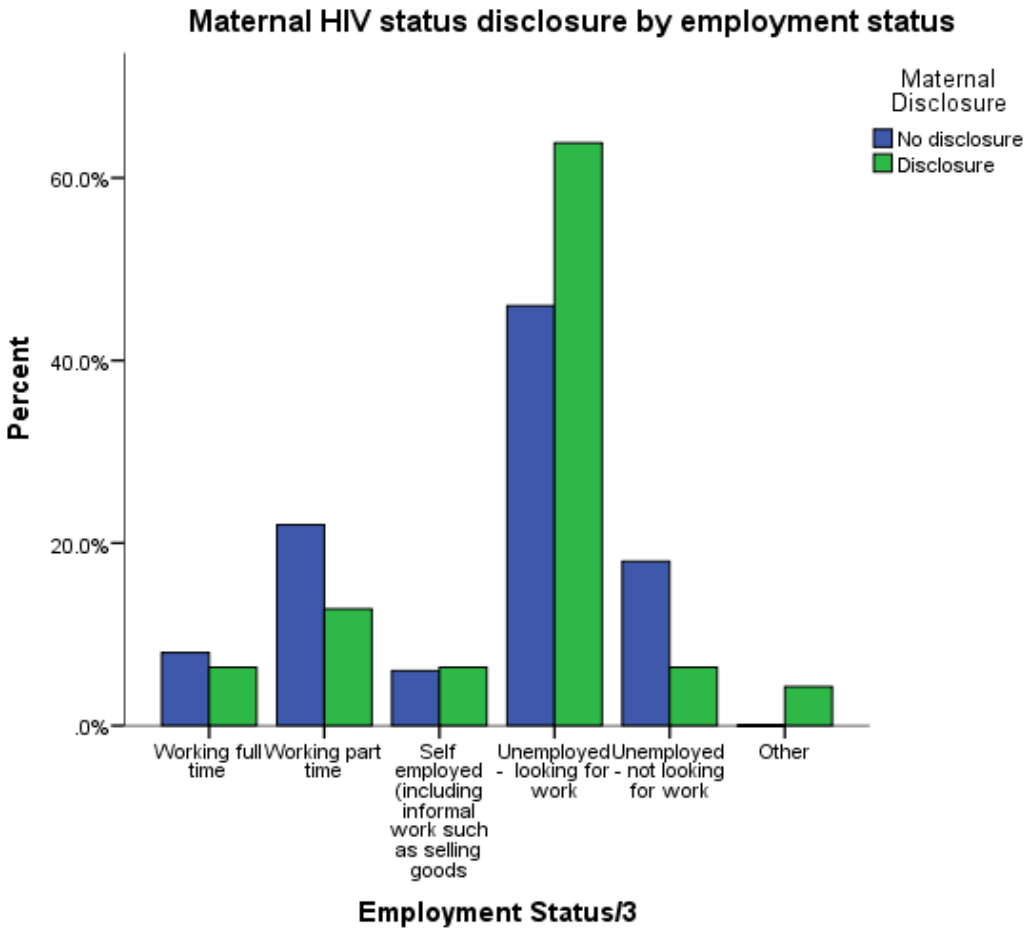

Figure 4.3.2: Clustered bar graph (% of number of cases) of maternal disclosure and employment status.

From Figure 4.3.2 it is clear that the majority of mothers were unemployed and looking for work. The graph also indicates that within the unemployed not looking for work category there were substantially higher percentage of mothers who did not disclose their HIV status when compared to the disclosure group. Similarly, within the working part-time category there were

substantially larger percentage who did not disclose their HIV status. It is interesting to note that in this study there were numerical differences in the unemployed category. There were slightly more mothers who disclosed in the category "unemployed and looking for work" whereas mothers who were employed had a lower disclosure rate. The Chi-square test for independence was conducted to explore the relationship between maternal disclosure and employment status. The Chi-square test (with Fisher's exact test) indicated no significant association between maternal disclosure and employment status, χ^2 (1, n = 97) = 7.1, p = 0.187, Cramer's V = 0.277. In this study there was no significant relationship between maternal HIV status disclosure and mothers' employment status.

4.3.3 Marital status and maternal HIV status disclosure

With regards to marital status within the no disclosure group (n = 50) results indicated that the majority of mothers (66%) were not married but had a partner, 18% indicated that they were married while 16% indicated that they were single and had no partner. In the disclosure group (n = 47) the majority of mothers (51.1%) indicated that they were not married but had a partner and 14% indicated that they were single with no partner (see Figure 4.3.3).

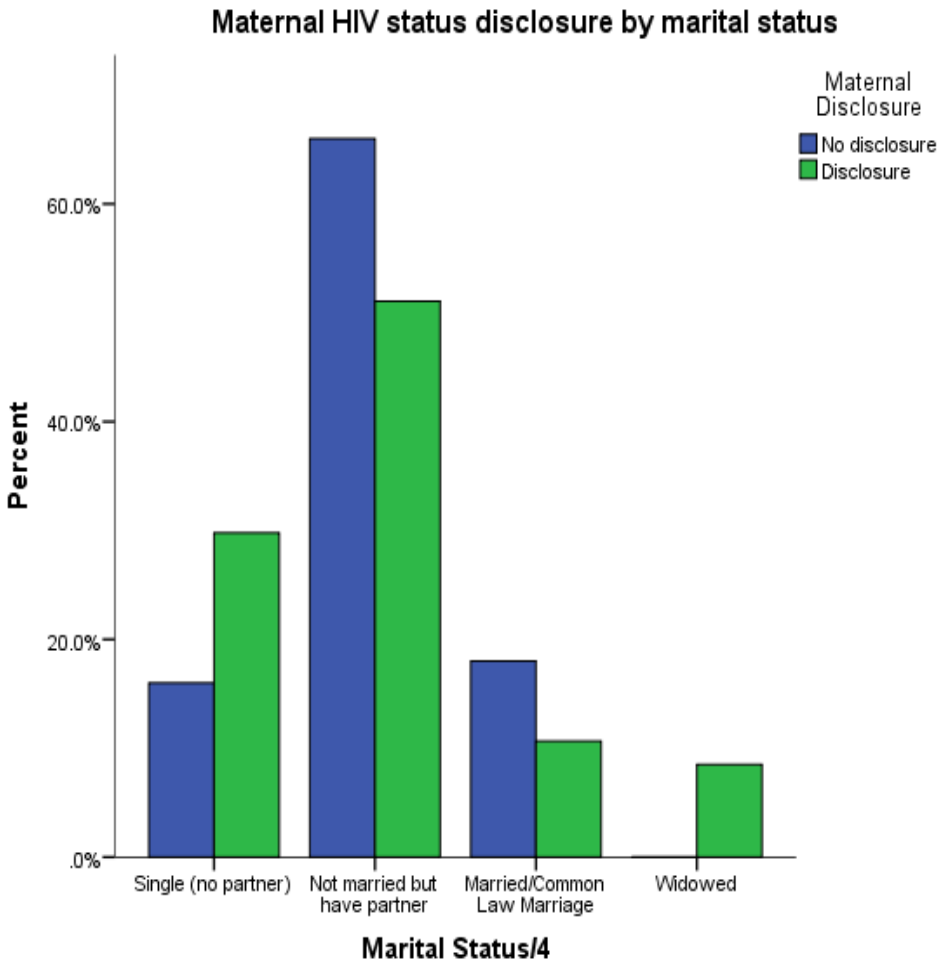

Figure 4.3.3: Clustered bar graph (% of number of cases) of maternal disclosure and marital status.

Figure 4.3.3 indicates that there are substantially higher proportion of mothers in the disclosure group who are single with no partner when compared to the non-disclosure group. Mothers who were married or those who were unmarried but had a partner were slightly more in the no disclosure group when compared to the disclosure group. The Chi-square test for independence (with Fisher's exact test) indicated a significant association between maternal disclosure and marital status, χ^2 (1, n = 97) = 7.74, p = 0.044, Cramer's V = 0.289. Therefore, in this study there is a significant relationship between maternal HIV status disclosure and a mother's marital status with a medium effect size (Cramer's V = 0.289). The results suggest

that mothers who were single were more likely to disclose their HIV status to their young uninfected children, whereas mothers who were married and those who had partners disclose significantly less.

4.3.4 Maternal disclosure and level of education

With regards to level of education within the no disclosure group (n = 50), the majority of mothers (55.1%) indicated that they had a high school level of education, and 18,4% mothers had primary school and a grade 12 level of education respectively. Mothers in the disclosure group (n = 47) indicated that the majority (48.9%) had a high school level of education: 29.8% had a grade 12 and 21.3% had a primary school level of education (see Figure 4.3.4).

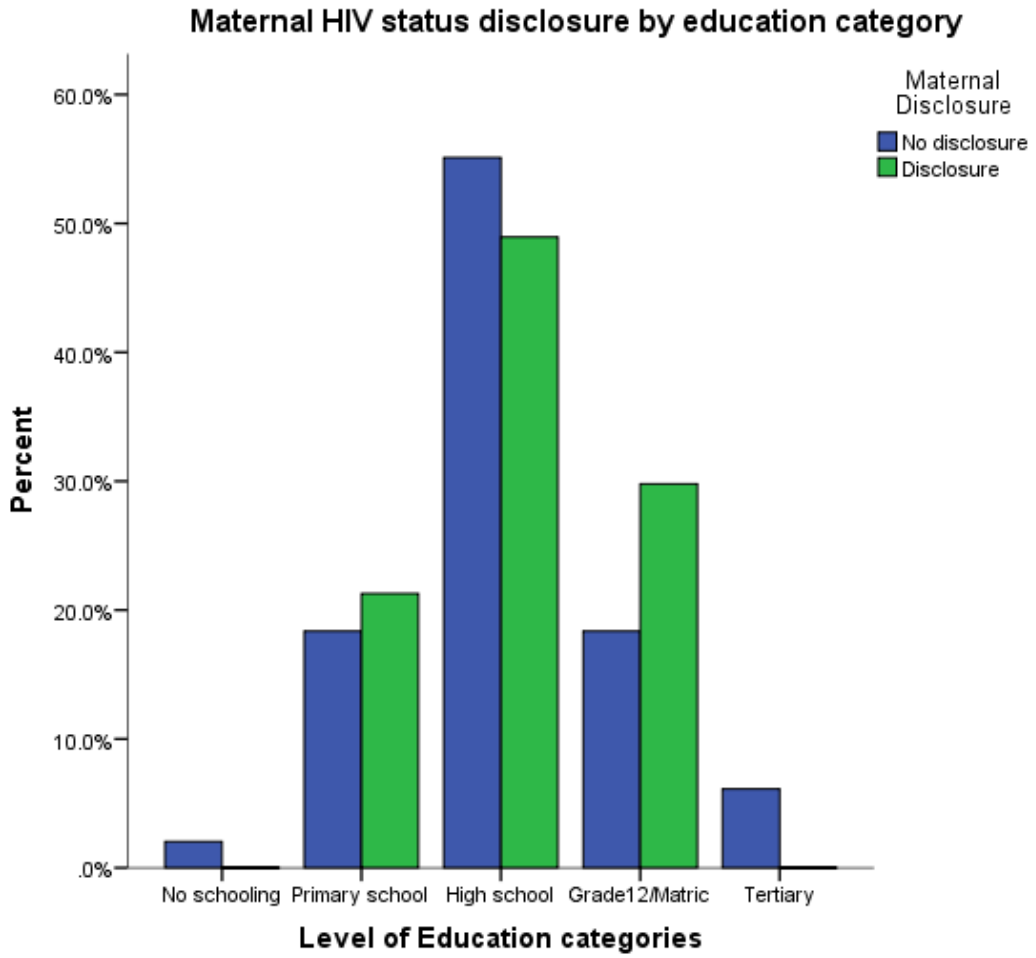

Figure 4.3.4: Clustered bar graph (% of number of cases) of maternal disclosure and level of education.

Figure 4.3.4 indicates that in this sample the majority of mothers completed high school as their highest level of education. There were slightly a larger percentage in the disclosure group who had a grade 12 and primary school level of education when compared to the non-disclosure group. There were slightly a larger percentage in the no disclosure group who had a high school level of education when compared to the disclosure group. To explore the relationship between level of education and maternal disclosure in the overall sample a Chi-square test of independence was performed on the data. The results (with Fisher's exact test) indicated no

significant association between maternal disclosure and level of education, χ^2 (1, n= 96) = 4.97, p = 0.254, Cramer's V = 0.238.

4.4 Comparisons of psychological variables between the groups

In this study non-parametric statistics were used to compare psychological variables in the two groups of mothers. According to Pallant (2010) non-parametric statistics do not make assumptions about the underlying population distribution. The Mann-Whitney U test was conducted to investigate if there were significant differences between the two groups of mothers in terms of their depression symptoms, coping style and parenting stress. The significant level was set at $p \leq 0.05$.

4.4.1 Comparison of groups: depression symptoms

As mentioned in Chapter 3 the CES-D scale was used to assess maternal depression symptoms. The five items assessing somatic symptoms were removed from the analysis because they are known to inflate depression scores in people living with HIV. The descriptive statistics reveal that the CES-D scale without somatic symptoms has a range of scores of 0-45, with M = 17.12 (*SD* = 11.09). These results indicate that the sample of mothers presented high levels of depression. In order to investigate whether mothers differ in terms of their scores on the CES-D scale, the first hypothesis (*There are significant differences in depression symptoms between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children*) was tested using the Mann-Whitney U test, the significant level set at $p \leq 0.05$. The results revealed no significant difference in the depression symptoms of mothers who disclosed (*Md* = 16, n = 47) and mothers who did not disclose (*Md* = 18.5, n = 50), U = 1146, z = -0.210, p = 0.83, r = 0.02). For this study (N = 97), the $\mathbf{H_1}$ is rejected since there are no significant differences between the two groups of mothers as the p-value is > 0.05.

4.4.2 Comparison of groups: coping style and coping strategies

The coping style of the mothers was assessed using the Brief Cope. As discussed in Chapter 3 the fourteen coping strategies were grouped into active coping and avoidant coping styles (Smith et al., 2001). High scores indicate regular use of a specific coping style to deal with life stressors. The descriptive statistics for active coping in the entire sample were: M = 51.82, range scores of scores of 30-64, (*SD* = 7.43), N = 97. Avoidant coping is made up of six coping strategies, giving a range of scores of 13-45. The descriptive statistics for avoidant coping in the entire sample were: M = 28.34 (*SD* = 6.52), N = 97.

In order to investigate whether mothers differ in their coping styles the second hypothesis (*There are significant differences in coping style between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children*) was tested using the Mann-Whitney U test, the significant level set at $p \leq 0.05$. The results revealed no significant difference in the active coping style of mothers who disclosed (*Md* = 53, n = 47) and mothers who did not disclose (*Md* = 52, n = 50), U = 966, z = -1.51, p = 0.131, r = 0.15). For this study (N = 97), mothers do not differ in terms of using active coping to deal with their life stressors. Similarly, the results revealed no significant difference in the avoidant coping style of mothers who disclosed (*Md* = 53, n =47) and mothers who did not disclose (*Md* = 52, n = 50), U = 1081, z = -0.68, p = 0.497, r =0.07). For this study (N = 97) the $\mathbf{H_1}$ is rejected since there were no significant differences between the two groups of mothers as the p value is > 0.05. Therefore, mothers do not differ in their coping styles.

Since mothers do not differ in their use of the two coping styles the researcher decided to investigate whether mothers differ in the use of each coping strategy. The Mann-Whitney U test was used in order to investigate whether mothers differ in the scores of each individual coping strategy. The results revealed that the mothers differ significantly in their use of the

following 4 coping strategies: *use of emotional support*, *use of instrumental support*, *self-blame* and *behavioural disengagement* (see Table 4).

Table 4: Significant differences in use of coping strategies

Name of coping strategy	Mean Rank scores	Mann-Whitney U results	Effect size
Use of emotional support	Mean rank scores for mothers who disclosed (55.13) and mothers who did not disclose (43.24).	There is a significant difference in the *Emotional support subscale* of mothers who disclosed (*Md* = 8, n =47) and mothers who did not disclose (*Md* = 7, n = 50), U = 887.5, z = -2.351, p = 0.019, r = 0.23.	Using Cohen's criteria this would be considered a small effect size, r = 0.2
Use of instrumental support	Mean rank scores for mothers who disclosed (55.99) and mothers who did not disclose (42.43).	There is a significant difference in the *Instrumental support subscale* of mothers who disclosed (*Md* =8, n =47) and mothers who did not disclose (*Md* = 6, n = 50), U = 846.5, z = -2.599, p = 0.009, r = 0.26.	Using Cohen's criteria this would be considered a medium effect size, r = 0.3
Self-blame	Mean rank scores for mothers who disclosed (43.03) and mothers who did not disclose (53.74).	There is a significant difference in the *Self-blame subscale* of mothers who disclosed (*Md* = 2, n =47) and mothers who did not disclose (*Md* = 4, n = 49), U = 894.5, z = -2.006, p = 0.045, r = 0.20.	Using Cohen's criteria this would be considered a small effect size, r = 0.2
Behavioural disengagement	Mean rank scores for mothers who disclosed (54.69) and mothers who did not disclose (43.65).	There is a significant difference in the *Behavioural disengagement subscale* of mothers who disclosed (*Md* = 5, n =47) and mothers who did not disclose (*Md* =5, n = 50), U = 907.5, z = -1.993, p = 0.046, r = 0.20.	Using Cohen's criteria this would be considered a small effect size, r = 0.2

4.4.3 Comparison of groups: parenting stress

The mother-child relationship was assessed by using the two sub-scales of the PSI; high scores indicating the presence of parenting stress. For this research, 11 items of the parenting distress subscale were used, giving a range of scores of 11-53. The descriptive statistics for the overall sample revealed: M = 29.10 (*SD* =8.87), N= 96. The Parent-Child Dysfunctional Interaction indicates the extent to which parents feel satisfied with their child and their interactions with them. High scores indicate the parent's lack of satisfaction with the interaction, thus indicating a parent's feeling of disappointment, rejection, or alienation by/from the child, or a lack of proper bonding with their child. The subscale has 12 items, giving a range of scores of 12-45. The descriptive statistics revealed: M = 25.22 (*SD* =7.30), N = 96.

In order to investigate whether mothers differ in the scores of their parenting stress the third hypothesis (*There are significant differences in parenting stress scores between mothers who have disclosed and mothers who have not disclosed their HIV status to their young uninfected children*) was tested using the Mann-Whitney U test, the significant level set at $p \leq .05$. The results revealed no significant difference in the Parenting Distress subscale of mothers who disclosed (*Md* = 26.5, n =46) and mothers who did not disclose (*Md* = 29, n = 50), U = 1047.5, z = -0.752, p = 0.452, r = 0.08). For this study (N=96), mothers do not differ in terms of their Parenting Distress scores.

The results also revealed no significant difference in the Parent-Child Dysfunctional Interaction scores of mothers who disclosed (*Md* = 24, n =46) and mothers who did not disclose (*Md* = 26, n = 50), U = 1043, z = -0.786, p = 0.432, r = 0.08). For this study $\mathbf{H_1}$ is rejected since no significant differences exist between the two groups of mothers as the p value is > 0.05. Therefore, mothers do not differ in their experience of parenting stress.

4.4.4 Summary of results

Table 5 gives a summary of the results in accordance with the aims and objectives of the current research: comparisons of psychological variables between the groups.

Table 5: Summary of results for comparison of groups: psychological variables

Scale	Sig. value	Result
CES-D scale	p = 0.834	No significant differences
Active coping style	p = 0.131	No significant differences
Use of Emotional Support	p = 0.019	Significant difference: disclosed group scored higher
Use of Instrumental Support	p = 0.009	Significant difference: disclosed group scored higher
Avoidant coping style	p = 0.497	No significant differences
Self-Blame	p = 0.045	Significant difference: non-disclosed group scored higher
Behavioural Disengagement	p = 0.046	Significant difference: disclosed group scored higher
Parenting Distress sub-scale	p = 0.452	No significant differences
Parent-Child Dysfunctional Interaction subscale	p = 0.432	No significant differences

4.5 Conclusion

This chapter provided the results for the research. The first section discussed descriptive statistics and demographic variables for all the mothers. The second section provided results pertaining to exploring significant associations between maternal disclosure and some

demographic variables. There was a significant association between maternal disclosure of HIV status and the marital status of the mothers, while the rest of the demographic variables showed no significant associations. Maternal psychological variables (depression symptoms, coping styles and parenting stress) were assessed for significant differences in terms of maternal HIV status disclosure. The results indicated no significant differences between the two groups of mothers in terms of psychological variables. However, some differences were found in the coping strategies of the two groups of mothers. The final chapter provides an integrated discussion of the results, as well as a discussion of the limitations and strengths of this research and provides some recommendations.

5. CHAPTER 5: DISCUSSION AND CONCLUSION

5.1 Introduction

The main objective of this study was to investigate whether there were differences in depression symptoms, coping style and parenting stress present in mothers who have disclosed their HIV status to their young uninfected children as opposed to those who have not disclosed. The secondary objective was to investigate whether significant associations exist between maternal disclosure of HIV status and maternal socio-demographic characteristics. This chapter presents a detailed discussion of the results in the context of current literature, the limitations of the study, recommendations for future research and a conclusion.

5.2 Maternal socio-demographic variables and significant association with maternal HIV status disclosure

The researcher explored the relationship between HIV status disclosure by mothers to their young uninfected children and the socio-demographic variables (maternal age, employment status, marital status and level of education) of these mothers. The researcher used a Chi-square test for independence to investigate whether there were statistically significant associations between maternal HIV status disclosure and socio-demographic variables. Marital status was found to be the only variable significantly associated with maternal HIV status disclosure.

5.2.1 Maternal age

In this study the results revealed that there is no significant relationship between maternal HIV status disclosure and a mother's age category. There is no literature about maternal disclosure to young uninfected children and maternal age. Previous research concerning women's disclosure of HIV status to their partners revealed a significant association between a woman's age and disclosure of HIV status. Older women were less likely to disclose their

status to their partners in a study conducted in Ukraine (Ahn et al., 2016). The same result is observed in the sub- Saharan region - younger women (those younger than 24 years) are more likely to disclose their HIV status to their partners when compared to older women (Medley et al., 2004). The current research shows that maternal age is not a statistically significant factor when mothers decide to disclose their HIV status to their young uninfected children.

5.2.2 Employment status

In this study there was no significant association between employment status and HIV status disclosure by mothers. There is no literature about maternal HIV disclosure to young uninfected children and maternal employment status. In a South African study non-disclosure of HIV status to a partner was significantly associated with having lost a job (Simbayi, et al., 2007) and in Tanzania, women who had a low-wage employment were less likely to disclose their HIV status to their partners (Antelman et al., 2001). This may imply that women who are economically dependent on a partner are less likely to disclose their HIV status to the partner. However, in the mother-child relationship context the mother's employment status is not a statistically significant factor when mothers decide to disclose their HIV status to their young uninfected children.

5.2.3 Marital status

As discussed in the literature review, previous research shows that, compared to those who are single, women who are married or cohabiting are more likely to disclose their HIV status to their partners than those who are single (Batte et al., 2015). In this research, however, we see the opposite. Mothers who are single with no partner and mothers who are widowed are more likely to disclose their HIV status to their young children than mothers who are married or who have a partner.

The researcher has a few opinions in this regard. In this study the results suggest that women who are married or cohabiting are significantly less likely to disclose their status to their young uninfected children. These mothers might have disclosed their status to their partners and therefore do not see the need to disclose their HIV status to their young uninfected children. Previous research can support this opinion because children, when compared to partners and other family members, are the least likely candidates for disclosure. Women living with HIV disclose more readily to their partners than to their children (Patel et al., 2012). Mothers have also cited fear of secondary disclosure by a child and concern about the emotional wellbeing of the child as reasons against disclosure (Mkwanazi et al., 2012). The researcher is of the opinion that a mother who is single might view her child as a means to immediate access to social support. Previous research supports this opinion in that mothers have cited help with household chores as one of the reasons for maternal HIV status disclosure to their children (Geiselhart et al., 2008).

5.2.4 Level of education

There is no literature which reports on maternal HIV disclosure to young uninfected children and maternal level of education. Previous research found that women who had a secondary education and higher, were more likely to disclose their HIV status to their partners than women who had a lower or no education (Batte et al., 2015). The same result was found in other developing countries in the sub-Saharan region. Women with a higher level of education were more likely to share their HIV status results with their partners than women who were illiterate or who had no schooling (Medley et al., 2004). Although mothers with no schooling are more likely to be associated with no disclosure, this study shows that there is no significant relationship between maternal HIV status disclosure and level of education.

In summary, factors associated with HIV disclosure in the context of the mother-child relationship are not the same as factors associated with women's HIV status disclosure to partners. From this study it seems that mothers disclose to their young children to gain support and closeness in the family.

Maternal HIV status disclosure and psychological variables

The main objective of the study was to investigate whether the two groups of mothers (those who disclosed and those who did not) differ significantly in their experience of depression symptoms, coping style and parenting stress.

5.2.5 Depression symptoms

Depression is a common disorder among people living with HIV. The experience of illness may exacerbate depression and it may also be a side effect of medication (Sherr, Clucas, Harding, Sibley, & Catalan, 2011). There is a lack of awareness with regard to mental health issues among patients and health-care workers; as a result, depression among people living with HIV often goes undetected (Andersen, Kagee, O'Cleirigh, Safren, & Joska, 2015). Compared to mothers who are HIV-negative the likelihood of clinical depression is high among mothers living with HIV (Johnson & Lobo, 2001). The results of this study indicate that mothers in both groups presented high levels of depression (scoring 16 and above on the CES-D scale). Although mothers in the disclosure group had lower levels of depression than the mothers who did not disclose, the difference was not statistically significant in this study. Previous research by Delaney et al. (2009) also found that mothers do not experience differences in depression based on their HIV status disclosure to their children. It was anticipated that disclosure to children could result in lower levels of depression symptoms as mothers would feel relieved from no longer having to keep their status a secret from their children. The data shows that these expectations did not materialise. According to the socio-

ecological approach, mothers are a part of larger social systems wherein maternal HIV status disclosure occurs in a complex and multidimensional environment. It is possible that other factors in the social system may contribute to mothers experiencing high levels of depression symptoms. For example, mothers who disclosed may worry about the children's ability to keep their HIV status a secret from community members, whilst mothers who did not disclose, worry about keeping their status a secret from the children and community members. There may be various factors that influence a mother's level of depression. For example, both groups of mothers could fear the consequences of HIV-related stigma. Another factor which may influence a mother's experience of depression symptoms is the social support received from her child or children and other family members. In previous studies mothers who disclosed their HIV status reported higher levels of social support in their lives than non-disclosing mothers (Murphy et al., 2011). It was also found that with increased family social support there was a significant decrease in depression (Delaney et al., 2009). The researcher is of the opinion that the actual and perceived social support received by mothers play a role in aiding mothers in their dilemma to disclose their HIV status to their young uninfected children.

Although there are no significant differences in the current study between the two groups of mothers based on their disclosure status, both groups of mothers showed high depression symptoms. The current research advocates for psychosocial support services for mothers during and after the disclosure process. In the Amagugu intervention, mothers presented significantly lower psychological distress symptoms such as depression and anxiety (as measured by the General Health Questionnaire) and there was an increase in maternal HIV status disclosure after the intervention (Rochat et al., 2015). Symptoms of depression among women living with HIV have been associated with poorer ART adherence, rapid disease progression and higher likelihood of AIDS-related mortality (Cook et al., 2014). Previous research (Cook et al., 2002) suggests that enhanced access to psychological services among

women may increase the use of ART. This research reiterates the need of mental health support services to aid mothers in dealing with their experience of depression symptoms and living with HIV. There is a shortage of mental health support services in South Africa's public health system; as a result, there is no guarantee for treatment of depression (Andersen et al., 2015). The researcher recommends that when planning interventions to promote maternal HIV status disclosure, there should be sessions specifically dedicated to alleviating the depression symptoms experienced by mothers living with HIV. From a socio-ecological perspective, maternal HIV disclosure is embedded in a dynamic and interactive social system. Although in this study maternal disclosure did not suggest an improvement in maternal mental health, other factors (such as the experience of stigma) in the social system might lead to high levels of depression symptoms among mothers. Therefore, psychological support services aimed at alleviating the experience of depression are essential to help mothers deal with their HIV status and their experience of stigma or other factors which might also play a role in mothers' disclosure dilemma.

5.2.6 Coping style and coping strategies

The Brief Cope scale was administered to all mothers. As mentioned in Chapter 3 the fourteen coping strategies were grouped into Active Coping and Avoidant Coping styles (Smith et al., 2001). In addition to dealing with the physical stressors of HIV infection, people living with the virus have to find effective coping mechanisms to deal with the stigma associated with having been diagnosed as HIV-positive (Mohanraj et al., 2015). As a result of the life stressors faced by mothers living with HIV, there is a need to identify effective coping strategies. Previous research (Hough et al., 2003; Medley et al., 2009) targeting people living with HIV, has shown that effective coping strategies are associated with ART adherence, effective stress management, decreased depression symptoms as well as better mental health and quality of life.

Active coping style is characterized by an individual's attempt to use his/her own resources to deal with the stressor. Active coping strategies aim to change the nature of the stressful situation or to modify how one thinks and feels about the stressful situation in order to alter one's reaction to the stressful situation (Carroll, 2013; Smith et al., 2001). In this study, the two groups of mothers do not differ in their use of *Active coping style* to deal with their life stressors. Mothers, however, differed in the *use of emotional support* and *instrumental support* as coping strategies.

- *Use of emotional support*: In the current research mothers who disclosed used this coping strategy significantly more than mothers who did not disclose their HIV status to their young uninfected children (See Table 4). The act of disclosing one's HIV status can be regarded as a form of coping with one's HIV diagnosis (Makin et al., 2008). Disclosure of HIV status to significant others and family is highly promoted as it is seen as the first step in securing support from family members (Crankshaw et al., 2014). Mothers therefore disclosed their HIV status to seemingly obtain support from their young child. Seeking emotional support is a coping strategy whereby an individual seeks out social support for emotional reasons. This strategy is characterized by obtaining support in the form of moral support, sympathy and understanding (Carver, Scheier, & Weintraub, 1989).
- *Use of instrumental support*: This study showed that mothers who disclosed used this coping strategy significantly more than mothers who did not disclose their HIV status to their young uninfected children (See Table 4). The researcher is of the opinion that mothers disclosed in order to obtain assistance from their children. In previous research (Geiselhart et al., 2008; Rwemisisi et al., 2008), mothers cited assistance with household responsibilities as one of the reasons for disclosing their HIV status. Instrumental support is a coping strategy whereby an individual seeks out social support for instrumental reasons. This strategy is characterized by seeking support for advice, information and assistance (Carver et al., 1989).

Avoidant coping style is characterised by an individual's cognitive and behavioural actions to avoid dealing with a stressful situation (Smith et al., 2001). In this study the researcher investigated whether the two groups of mothers differed significantly in their use of avoidant coping style. The results revealed that mothers did not differ in their use of *Avoidant coping style* to deal with their life stressors. However, mothers differed significantly in their use of some coping strategies which form part of the avoidant coping style. Mothers differed in the use of the following coping strategies: *Self-blame* and *Behavioural disengagement*.

- *Self-blame*: In the current study mothers who did not disclose their HIV-positive status to their young uninfected children used self-blame as a coping strategy significantly more than mothers who disclosed (See Table 4). The researcher is of the opinion that mothers might feel guilty and blame themselves for being diagnosed with HIV. As a result, they might not want to share their diagnosis with their children because they believe that it might be an emotional burden on the child. This opinion can be supported by previous research whereby mothers who did not disclose cited the possible emotional burden as a reason for non-disclosure. They feel that a child deserves a care-free childhood and mothers believe disclosing their HIV status would be too much of an emotional burden on a child (Schrimshaw & Siegel, 2002). Self-blame is a coping strategy which involves blaming, criticizing oneself and negative introspection. The individual attributes the stressful situation he/she is experiencing directly to his/her actions or character (Hooker, 2013). In people living with HIV and AIDS, self-blame is closely associated with internalised HIV-stigma (Kotze et al., 2013).

- *Behavioural disengagement*: In this study, mothers who disclosed used this coping strategy significantly more than mothers who did not disclose their HIV status to their young uninfected children (See Table 4). Behavioural disengagement is a coping strategy characterized by an individual's attempts to reduce his/her efforts to deal with the stressor. This includes even giving up trying to attain goals with which the stressor is interfering. This coping

strategy is reflected in actions or behaviour that symbolise helplessness (Carver et al., 1989). The researcher is of the opinion that mothers who use this coping strategy behave in a way that shows that they have lost interest in attaining their goals because they have been diagnosed as HIV-positive. The children might worry and enquire about the mother's behaviour (giving up and withdrawing from attaining goals). A child's queries might lead to a mother disclosing her HIV status. Previous research shows that children's queries with regards to maternal health may also influence disclosure (Murphy, 2008). It is possible that in this context, children's queries about a mother's change in behaviour might influence disclosure.

The results of this research suggest that mothers do not differ in their use of overall *coping styles* based on their disclosure status. Previous research (Kotze et al., 2013) using a South African sample showed no association between coping style and disclosure of HIV status to partners and family members among pregnant women.

The results of this study also suggest that the two groups of mothers differ significantly in the use of some *coping strategies*. Mothers who disclosed used support seeking (use of emotional and instrumental support) significantly more as a coping strategy whilst mothers who did not disclose showed significantly more self-blame. This result is particularly important because research suggests that mothers are willing to disclose their HIV status to their young uninfected children, however they do not feel that they are adequately equipped to do so (Mkwanazi et al., 2012). In order for mothers to feel equipped to undertake disclosure, the researcher is of the opinion that mothers could be encouraged to engage in more active coping strategies, such as seeking instrumental support, the provision of assistance and information about: effective parenting techniques, disclosure of one's HIV status to a child and family members, as well as self-care and healthy living. Such information would be useful in helping mothers balance their daily life demands and cope with being diagnosed with a chronic illness. Chida and Vedhara (2009) found active coping to be associated with positive health and

psychosocial outcomes in people living with HIV and AIDS. Mothers who engage in avoidant coping strategies are less likely to disclose their HIV status because it indicates how they deal with the HIV diagnosis. Avoidant coping is associated with negative health and psychosocial outcomes such as an increase in HIV and AIDS related symptoms, non-disclosure of a positive HIV status and non-adherence to ARV treatment (Chida & Vedhara, 2009; Simoni et al., 2000).

5.2.7 Parenting stress

The current study investigated whether significant differences in the context of the mother-child relationship (as assessed by the presence of parenting stress) exist between mothers who disclose and those who do not disclose. In particular, this study investigated whether the two groups of mothers differ in their scores of parenting stress for the two subscales of the parenting stress index (Parental Distress and Parent-Child Interaction subscales). Mothers who disclosed scored less in the Parenting Distress subscale, although not statistically significant when compared to mothers who did not disclose. Similarly, no significant difference was observed in the Parent-Child Dysfunctional Interaction scores of mothers who disclosed and mothers who did not disclose. The results suggest that mothers do not differ in their experience of parenting stress based on their HIV disclosure status. In relation to this, the socio-ecological perspective shows that the mother-child relationship manifests in the larger social system. The researcher is of the opinion that other factors in the social system may contribute to mothers' experience of parenting stress. Poor physical health and the effect of HIV on the mental health of mothers have been identified as factors contributing to compromised parenting (Murphy et al., 2009). For example, a factor such as custody planning may contribute to mothers experiencing high parenting stress as they may be worried about who will care for their children in the event of their hospitalization or illness. The Amagugu intervention addresses this phenomenon by including information about custody planning as part of the intervention

sessions (Rochat et al., 2013). After the Amagugu intervention, there was a significant decrease in the parenting stress score of mothers (Rochat et al., 2015)

In this study, both groups of mothers present high scores for parenting stress. The high scores of parenting stress in both groups of mothers are consistent with past research that indicated that parents with poor health reported more parenting stress than healthy parents (Murphy et al., 2010). Previous research shows that parents living with HIV express anxiety about their capability to meet their children's needs and do not feel well equipped to deal with parenting issues (Murphy et al., 2015). High levels of anxiety in parents have been associated with poor parenting practices such as reduced monitoring and control. Mothers living with HIV have reported that their greatest source of stress is balancing maternal and psychological demands with the demands of living and coping with a chronic disease (Murphy et al., 2010). The stressors associated with an HIV diagnosis can compromise a mother's mental health, which can be directly related to her parenting capacity (Boeving-Allen et al., 2014).

5.3 Limitations of the study and recommendations for future research

The most notable limitation of the current study is that this research is a secondary analysis of previous research, namely the Kgolo Mmogo project. The researcher did not devise the original research survey, therefore some variables of interest which could have been used in this current study such, as social support and stigma, were not addressed in the original study. Another limitation is the small sample size. In the original research only 11.6 % of the 408 mothers in the study disclosed their HIV status to their young uninfected children. As a result, data analysis for this research was conducted on an overall sample of 97 mothers (47 mothers who disclosed and 50 who mothers did not disclose were randomly selected from the non-disclosing mothers in the Kgolo Mmogo sample). Moreover, the self-reporting measures used in the study have some inherent limitations. However, the results of the current study provide

meaningful insight into the challenges of mothers living with HIV who have young uninfected children. The results of this study are based on mothers who volunteered to participate in the Kgolo Mmogo project and they represent a portion of the population of mothers living with HIV in Tshwane. Further research needs to be conducted using a larger sample which can represent all South African women living with HIV.

One of the biggest limitations is that this research is a cross sectional study where two groups of mothers was compared in terms of psychological variables. Longitudinal data is needed to understand whether the findings determined disclosure (e.g. whether experiencing high depression symptoms resulted in mothers disclosing or prompted mothers to disclose) or if the findings are a consequence of disclosure (e.g. mothers experience high depression symptoms because they disclosed). In this study the results are interpreted using the latter perspective. This study used baseline data in which mothers who enrolled in the Kgolo Mmogo project had already disclosed their HIV status before baseline measurements (depression symptoms, coping and parenting stress) were taken. Another limitation might be the presence of selection bias in the sampling approach for obtaining a sub-sample for the non-disclosing group. There is a risk of systematic bias in a small sample size (n = 97).

The researcher recommends that future researchers include other variables such as social support, stigma and maternal health. The researcher also recommends that future researchers investigate the relationships between the variables of interest (e.g. demographics, depression symptoms, coping, stigma, social support, parenting stress etc.) as opposed to only comparing groups on variables. In this study the researcher could not investigate the relationships between the variables due to the small sample size.

The researcher also recommends that interventions be introduced to assist mothers to disclose their HIV status to their children, similar to the Teaching, Raising, And

Communicating with Kids (TRACK) program. The TRACK program was a longitudinal pilot trial intervention which was designed to help mothers living with HIV to disclose their HIV status to their young children in the 6-12 age group (Murphy et al., 2011). The results indicate that 33% of mothers in the intervention group disclosed as opposed to 7.3% in the control group (Murphy et al., 2011). The intervention increased self-efficacy to disclose. In the context of the parent-child relationship communication between mother and child improved (Murphy et al., 2011). The researcher recommends that future researchers plan for culturally and developmentally appropriate interventions that can assist mothers in disclosing their HIV status to young uninfected children. The intervention should also aim to help mothers cope with their HIV diagnosis and reduce their high depression levels and parenting stress. There is a need for such interventions within the sub-Saharan African context. In general, disclosure improves adherence to ART and enhances close family relationships (Fisher & Cooper, 2012; Tenzek et al., 2013).

5.4 Final conclusion

Over time the course of HIV has changed from a deadly virus to a chronic manageable disease. Mothers living with HIV live longer to raise their young uninfected children. These mothers now have to deal with the question of how and when to disclose their HIV status to their children (Bor et al., 2013; Dass-Brailsford et al., 2014). In this study the marital status of mothers was significantly associated with maternal HIV status disclosure, with mothers who are single and widowed disclosing their HIV status significantly more to their young uninfected children. Mothers who are single might view a child as an immediate source of social support. Socio-demographic factors associated with HIV disclosure in the context of the mother-child relationship are not the same as factors associated with women's HIV status disclosure to partners.

The researcher's findings indicated that mothers in the two disclosure groups do not differ significantly in their experience of psychological variables (depression symptoms, coping style and parenting stress). These results suggest that maternal psychological functioning does not differ by disclosure of HIV status to young uninfected children at baseline. Previous research has shown that when maternal HIV status disclosure is coupled with social support there is an improvement in maternal mental health (Delany et al., 2009; Mkwanazi et al., 2012; Simoni et al., 2000). All mothers regardless of HIV disclosure status presented high depression symptoms and high scores in parenting stress. Mothers do not differ in the use of overall coping styles; however, they differ in the coping strategies they use. Mothers who disclosed tend to use support seeking and behavioural disengagement as coping strategies significantly more than mothers who did not disclose, while the latter used self-blame significantly more than disclosing mothers. These results have an implication for HIV and AIDS care services as there is an indication that there is a need for mental health support services for mothers living with HIV who are facing the dilemma of disclosing their HIV status to their young uninfected children. The current research provides evidence for psychosocial support services to form an integral part of HIV and AIDS routine healthcare. Providing such services may improve coping and reduce psychological distress and lead to higher rates of disclosure. This is important because maternal disclosure has documented benefits for both mother and child. The results of this study are essential as they form part of the body of research as well as a basis to understand maternal psychological functioning in the context of disclosing HIV status to young uninfected children. Such information would be helpful in determining the content for future research directed at planning interventions to promote and optimize maternal disclosure. In addition, this study creates awareness of the complexity of maternal HIV disclosure and provides more information on the self-reported psychological variables of mothers living with HIV. This

research, in addition, also provided insight into the impact of disclosure on the well-being of the mothers concerned.

In conclusion, maternal HIV status disclosure is a complex phenomenon which takes place in the context of a larger social system. It is important to employ individual-focused and environment-focused strategies to optimize disclosure and improve maternal psychological functioning.

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APPENDIX A

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities
Department of Psychology

2 Maart 2016

Dear Amukelani

RE: Permission to use existing research data

Hereby I give you permission to use the research data collected as part of the Kgolo Mogo project for your mini-dissertation. This was cleared with all the role players and project leaders of the project namely Prof Irma Eloff and Prof Brian Forsyth. They gave permission that you may access to the data for analysis. This section of the data has not been analysed before.

The Kgolo Mogo project was done from 2006 to 2014. It involved a large research team and various phases. Various research topics are thus possible from this project. Each team member could identify an area he/she would like to work on. I have identified the area of disclosure which is the topic involved in this research. You thus collaborate in this project by analysing the data I would have done.

The Kgolo Mogo project received ethical clearance from the Ethical committee of the Medical Faculty and Yale University (included). Strict ethical procedures were followed during data collection with each participant giving informed consent (included). The informed consent does not state that data can be re-used for further research. Though, this research does not involve the re-use of data or further research. This project is part of the analysis of a section of the data that has not been analysed before. It is thus still part of the research that the participants gave consent for. There is no identifying information about the participants in the data set, therefore data will be handled confidentially and re-consent is impossible (and unethical). This analysis of the data will enhance our thinking about disclosure of HIV status to children and can in no way be harmful to any of the participants.

Yours faithfully,

Prof Maretha Visser
Supervisor

Humanities Building, Room 11 - 12
Lynnwood Road, PRETORIA, 0002
Republic of South Africa
Tel: +27 12 420 2549
Fax: +27 12 420 3479
www.up.ac.za
maretha.visser@up.ac.za

APPENDIX B

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

24 February 2017

Dear Prof Maree

Project:	**Psychological variables and maternal HIV status disclosure to young uninfected children**
Researcher:	**AJ Hlungwani**
Supervisor:	**Prof M Visser amd Ms TA Thomas**
Department:	**Psychology**
Reference number:	**29282617 (GW20170216HS)**

Thank you for the application that was submitted for ethical consideratic n. The Committee notes that is an application for secondary data analysis and that permission was granted by the initial researcher to use the data.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 23 February 2017. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:tracey.andrew@up.ac.za

APPENDIX C

Kgolo Mmogo Sociodemographic Questionnaire

(Mother focused questions- part 1)

KM ID #_____ Date: (dd/mm/yyyy) _____

Thank you for being willing to talk to us. We need to understand your experiences with HIV to enable us to develop ways of helping families similar to yours. First, I am going to ask you questions about yourself so that I can understand who you are and know a little bit about your background.

1. How old were you on your last birthday? _____

2. What is the highest grade you completed in school? (Please indicate with a X)

☐ Grade 0 1 2 3 4 5 6 7 8 9 10 11 12 Tertiary

3. Which of the following best describes your current employment status?

☐ Working full time
☐ Working part time
☐ Self-employed (including informal work such as selling goods at the market)
☐ Unemployed - looking for work
☐ Unemployed – not looking for work
☐ Other

4. Which of the following best describes your current marital status?

☐ Single (no partner)
☐ Not married but have a partner
☐ Married/Common Law Marriage
☐ Widowed

Finally, I would like to know what you have told your child about your health. Remember, we are not going to share any of your health information with your child. We only want to know what kinds of talks, if any, you have had with your child about your health.

143b. What have you told your child about your HIV status?

☐ I have told my child I have HIV/AIDS.
☐ Someone else told my child that I have HIV/AIDS.
☐ I have told my child I have a serious health/medical condition, but not that it is HIV.
☐ I have told my child that I have something wrong with me, but have not said that it is serious.
☐ I have not told my child anything about my health.