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# Experiences of Women Recently Diagnosed With HIV

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by

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Supervised by

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# DECLARATION

I declare that **Experiences of women recently diagnosed with HIV** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before any other degree at any other institution.

**SIGNATURE** **DATE**
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# ABSTRACT

The focus of this study is on the experiences of a small sample of local women who have been recently diagnosed with HIV. The aim of the research was to give these women an opportunity to express their first-hand, personal accounts of living with HIV. Five isiXhosa-speaking women were recruited and interviewed. These accounts were collected and analysed within in the methodological framework of Interpretative Phenomenological Analysis, a qualitative approach that is becoming increasingly popular in the broad fields of health and clinical psychology. Data was analysed for meaningful units, which were interpreted inductively and hermeneutically, and categorised into super-ordinate themes. Five themes within the participants' experiences of living with HIV were identified: (1) *experiences of diagnosis*, (2) *experiences of stigma*, (3) *social support*, (4) *coping strategies*, and (5) *HIV as one of many assaults to self*. Implicated in these experiences are the ways in which these women have appraised themselves and their situation after an HIV-positive diagnosis, appraisals that are shaped by HIV-related stigma. A variety of negative emotional reactions are common following the diagnosis, often compounded by the direct experiences of HIV-related stigma. Women in the study adopted different kinds of coping strategies based on the resources and social support available to them. Also significant is that for these women who had typically endured a variety of traumatic life events, a positive diagnosis was simply one of many life challenges.

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# CHAPTER ONE: INTRODUCTION

## 1.1 Introduction

This introductory chapter provides the reader an overview of the HIV/AIDS epidemic in Sub-Saharan Africa. It also highlights the significant issues that appear to have exacerbated and might still be contributing to the high incidence of HIV infection in the Southern African sub-continent. A particular emphasis is paid to women as they seem to be the most vulnerable group due to multiple factors, which is the reason for focusing the current study on women. The chapter will conclude by outlining the structure of this thesis, explaining what each of the chapters entails.

## 1.2 HIV and Women in South Africa

Sub-Saharan African carries the burden of the global HIV infections (UNAIDS, 2010). South Africa has the highest number of people with HIV in the world, where the national prevalence is 12.2% (Shisana et al., 2014), and where AIDS remains a leading cause of death (Myer, Seedat, Stein & William, 2009). When disaggregated, the national prevalence amongst women is estimated to be 14.4% and amongst men, 9.9% (Shisana et al., 2014). Most worryingly, the HIV incidence amongst women in the age range of 15 to 24 is four times higher than men in this age group, and the prevalence peaks amongst women aged between 30 to 34 (Shisana et al., 2014). On average, women are infected five years earlier than men (Ackerman & de Klerk, 2002; Jewkes, 2009). One part of the explanation for this is that women have biological susceptibility to do with the surface area of the vagina (Ackerman & de Klerk, 2002). Another biological factor that confers particular vulnerability on women is to do with the difficulty of identifying and treating other sexually transmitted infections, which increases the likelihood of HIV infection (Ackerman & de Klerk, 2002). Yet biological vulnerabilities are only part of the explanation: the rest is to do with inequitable gender norms and gender roles (Jewkes, 2009; Smith, 2002).

These other factors include gender-based violence, poverty and inequitable gender roles (Ackerman & de Klerk, 2002; Jewkes, 2009; Jewkes, Dunkle, Nduna & Shai, 2010). Such factors stem from the patriarchal system, which supports and demands male domination (Hoosen & Collins, 2004; Leclerc-Madlala, Simbayi & Cloete, 2009). Such patriarchal practices include the payment of Lobola or dowry and polygamous marriages (Lawson, 1999; Thomas, 2007). Both provide men with entitlement over women (Lawson, 1999; Thomas, 2007), who are often expected to obey men and submit to men's demands (Hoosen & Collins, 2004; Simbayi et al., 2005).

These dynamics also often leave women economically dependent on men as cultural norms and gender roles leave women with fewer chances of employment (Ackerman & de Klerk, 2002; Ciambrone, 2001; Thomas, 2007). They are expected to bear and raise children and do household work, with little assistance from their male partners, which inevitably places them in a financially dependent position (Ackerman & de Klerk, 2002; Doyal & Anderson, 2001; Ciambrone, 2001). Furthermore, financial dependence deprives women of the freedom to end abusive relationships for fear of losing their only source of financial support (Ackerman & de Klerk, 2002; Jewkes, 2009). Also important to note is that that women are often physically and sexual abused by their partners (Ackerman & de Klerk, 2002). Gender-based violence puts women at heightened risk of contracting HIV infection because it often leaves them disempowered and less able to refuse or negotiate safe sex (Jewkes, Levin & Penn-Kekana, 2003). Thus the threat of violence and actual financial dependence work together to deprive women of the power they need to protect themselves from HIV infection (Ackerman & de Klerk, 2002; Jewkes, 2009; Jewkes, et al., 2003).

Women living in poverty are the most vulnerable of all. Poverty is defined as "a condition characterised by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on income but also on access to social services" (Noble, Ratcliffe, & Wright, 2004, p. 6). Poverty appears to have a circular relationship with HIV/AIDS (Lau & Muula, 2004).

HIV puts people at risk of poverty: An individual may become sick, which may lead to unpaid absenteeism, loss of employment and death; additionally, others lose their jobs because of the demands of caring for a family member who is ill; whilst the medical costs of seeking and obtaining treatment can be a financial burden on families (Rodrigo & Rajapakse, 2010; Shisana, Pezi & Zungu, 2009). Yet poverty also puts people at risk of HIV infection: Many people living in impoverished conditions that demand daily survival are perhaps less able to be concerned about the more long-term risks of HIV and engage in risk transactional sex for survival (Shisana et al., 2009).

Adding to the trauma of the psychosocial problems associated with HIV is stigma. Stigma has been defined by various scholars in many different ways, but for the purpose of this study, Deacon, Stephney and Prosalendis' (2005) definition is deemed most suitable. According to these authors, "Disease stigma can be defined as an ideology that claims that people with a specific disease are different from 'normal' society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or groups in society. Disease stigma is thus negative social 'baggage' associated with a disease" (2005, p.19).

Stigma contributes to the spread of HIV/AIDS because people are often compelled to conceal their status due to fear of rejection and discrimination (Gilbert & Walker, 2010; Skinner & Mfecane, 2004). Described as the second epidemic (Carr & Grambling, 2004), stigma is deeply implicated in the stress and mental health challenges that are associated with HIV (Plattner & Meiring, 2006; Young, 2011).

By encouraging people to conceal their status, stigma deprives people of opportunities to obtain necessary social support (Lekganyane & du Plessis, 2012; Medley, Kennedy, Lunyolo & Sweat, 2009). The threat of stigma and discrimination makes disclosure an unviable option for too many people who live with HIV (Gilbert & Walker, 2010). The fear of stigma explains why so many opt only for a partial disclosure, where they can only disclose their status only to people deemed safe and conceal their status from others (Haricharan, 2010). A lack of social support can lead to poor coping skills, which can contribute to the development and maintenance of mental health problems (Brandt, Dawes & Bray, 2006; Hinton & Earnest, 2010).

People infected with HIV/AIDS carry an elevated prevalence of mental illness (Freeman, Nkomo, Kafaar & Kelly, 2007). This does not practically mean that everyone diagnosed with HIV will develop mental health problems, it rather suggests that the burden of mental disorder is higher for those who are HIV-positive than it is for those who are not; additionally, like poverty, mental illness is both a cause and consequence of HIV infection (Freeman et al., 2007; Kelly, Freeman, Nkomo & Ntlabati, 2008). The three most common psychological disorders that have been identified in people living with HIV/AIDS (PLHA) are depression, substance abuse and posttraumatic stress disorder (Kelly, et al 2008).

## 1.3 Problem Statement

The current study focuses on the experiences of a small sample of isiXhosa-speaking women who have been recently diagnosed with HIV. The researcher is interested in exploring the meaning these women attach to their HIV-positive diagnosis in the context of stigma and possible implications for their psychological adjustment and mental health. Interpretive

Phenomenological Analysis (IPA) was used as the methodological framework. IPA is a qualitative approach that focuses on the experiences of people and the meaning that these people make of their experiences. The aim of the study was to provide these women with an opportunity to express their experiences in their mother-tongue; this is important because monolingual isiXhosa speakers are often excluded from participation in studies that are conducted in either English or Afrikaans.

## 1. 4 Overview of the Study

Chapter Two, which follows this introductory chapter, is a review of literature relevant to the study, which aims to draw parallels between global and local studies around HIV/ AIDS, Stigma and Mental Health. Chapter Three describes the qualitative methodology that was employed to meet the aims of the study Issues of validity and ethics are also discussed in this chapter. Chapter Four comprises a presentation of the research findings, which are the super-ordinate themes that emerge from the analysis, and a discussion of these themes. Chapter Five is a conclusion of the entire study which includes critical evaluation of the study, and which also presents recommendations for future research.

## 1.5 Conclusion

Chapter One serves to orientate the reader to the study by providing a brief overview and the necessary background information. This chapter highlighted some of the contributing factors to the spread of HIV infection in Sub-Saharan Africa as well as reasons for women's vulnerability to HIV infection. The discussion of these issues is developed in the next chapter.

# CHAPTER TWO: LITERATURE REVIEW

## 2.1 Introduction

While there have been vast amounts of research conducted on the HIV pandemic in South Africa, very little on the relationship between HIV/AIDS and mental health (Breuer, Myer, Struther & Joska, 2011**).** What little research that does exist on HIV/AIDS and mental health suggests that the burden of mental disorder is higher for those who are HIV-positive than it is for those who are not, and that of all the psychological disorders, depression appears to be the most common among people living with HIV/AIDS, followed by substance abuse and posttraumatic disorder (Kelly et al., 2008).

Furthermore, other people may experience more severe forms of psychological distress when they hear that they are HIV-positive (Ostrow, & Defranceisco, 1996). Such mental disorders might lead to a different view about self (Ciambrone, 2001). According to Young (2011), there are many problematic ways in which people will appraise themselves following the diagnosis of HIV, including viewing themselves as immoral, frail, deprived and dying. He suggests further that negative self-appraisals following the diagnosis of HIV are more likely in a social context that supports such appraisals (Young, 2011). In light of stigma that surrounds HIV, negative self-appraisals are more likely following HIV diagnosis; as evident in a study of women infected with HIV, and social stigma was the strongest predictor of PTSD severity (Katz, & Nevid, 2005).

Moreover, an HIV-positive diagnosis is also considered a traumatic event (Stevens & Doerr, 1997). For many the diagnosis usually means a sudden shortened life because of the poor prognosis of HIV/AIDS and the perception of an HIV-positive diagnosis as a representation of imminent death, which is often associated to continued physical weakness and stigma (Green & Sobo 2000; Holt et al., 1998; Plattner & Meiring, 2006). Therefore in order to deal with the trauma, individuals need to develop coping strategies (Green & Sobo, 2000). Social support becomes fundamental source in developing coping strategies, in order to ensure psychological adjustment (Hinton & Earnest, 2010; Pergami et al., 1993).

This review of the literature starts with a discussion of HIV-related stigma and its relationship with the trauma often associated with being diagnosed as HIV-positive, followed by the mental health consequences of HIV and the various psychosocial factors that impact on women's experience of HIV, including gender inequality, violence and poverty.

## 2.2 HIV/ AIDS Stigma

HIV/AIDS is by far one of the highly stigmatised illnesses for various reasons, which may include perceptions about the nature of transmission, course of the illness, contagion and spiritual beliefs (Herek, 1999; Parker & Aggleton, 2003). HIV/AIDS is understood to evoke stigma and discrimination for various reasons. HIV/AIDS is often perceived to be contracted through 'irresponsible' behaviour that can be avoided or a person is perceived to have the ability to prevent infection by taking better 'moral' decisions (Deacon, 2006; Gilbert & Walker, 2010; Skinner & Mfecane, 2004). People who contract the virus are often perceived to be 'responsible' for being infected (Herek, 1999), and often associated with those who are already marginalised. They may also be stigmatised because of the perception that AIDS is a fatal condition (Herek, 1999). HIV infection is viewed as a disease that will advance in time and that it has no cure, therefore people assume that when an individual is diagnosed with the virus death is imminent (Plattner & Meiring, 2006). The understanding of HIV as a contagious illness can also increases the likelihood of stigma because people living with HIV/AIDS might be perceived as a threat or danger in their communities, which also leads to discrimination (Herek, 1999). Moreover, when those that are infected reach the final stages of AIDS they may become symptomatic from the AIDS-related illnesses to a point where they can no longer hide the symptoms and may appear frail and weak (Gilbert & Walker 2010; Herek, 1999).

Factors that usually aggravate stigma are poverty and being from disadvantaged groups like women (USAID, 2006; Shamos, Hartwig, & Zindela, 2009). Different types of stigma namely internalised or felt stigma, received stigma or enacted, associated or courtesy stigma and symbolic stigma are discussed below.

### 2.2.1 Internalised stigma

According to Simbayi et al. (2007), people living with HIV/AIDS tend to internalise stigma and this plays a major role on the emotional reactions experienced by HIV-positive people. Internalised stigma is defined as “thoughts and behaviours stemming from the person’s own negative perceptions about him- or herself, based on his or her HIV status” (Greef, et al., 2008, p.313). People that internalise stigma may feel ashamed and may have feelings of guilt because they feel they have humiliated their families by being infected with HIV (Simbayi et al., 2007; Greef & Phetlhu, 2007). They may also blame themselves for being stigmatised because they feel they deserve to be punished for their disappointing behaviour (Herek et al., 1998). Shamos, et al., (2009) argue that people that suffer from internal stigma may anticipate that they will be unable to secure employment, maintain a current job or will be mistreated by their colleagues. More importantly, this internalisation of stigma has a significant impact on the quality of life because when people expect stigma they deny themselves of support, by isolating themselves and avoiding social or family gatherings, which would help them gain more self-esteem Greef et al., 2008; Thomas et al., 2005).

Internalised stigma has also been associated with the development of depressive symptoms, as some people conceal their status, which then lead to risky behaviour as those that are infected may not negotiate condom use, in fear of raising suspicion about their status (Herek, 1999;

Thomas et al., 2005). The psychological understanding proposed by USAID (2006) is that people that experience internal stigma have past experiences of shame and blame from others and it usually in situations where families are not prepared to associate with people that have HIV. This may become evident in how the infected member of the family is treated, for example the family members may reject the infected person and may subsequently escalate into acts of discrimination or violent behaviour which is known as received or enacted stigma (Dlamini et al., 2008; Makoae et al., 2008).

### 2.2.2 Received Stigma

Received stigma refers to "stigmatising behaviour of neglecting, fearing contagion, avoiding, rejecting, labelling, pestering negating, abusing and gossiping about persons living with HIV/AIDS as experienced or described by themselves or others" (Greef et al., 2008, p. 313). This type of stigma manifest in the form of actual acts of discrimination where people lose their jobs or would be denied access to basic services like health care or housing projects because of their HIV status (Shamos et al., 2009). The most common form of received stigma is verbal and physical abuse, which is usually a manifestation of the rejecting and isolating behaviour directed at people living with HIV/AIDS (Dlamini et al., 2008). The worst examples in South Africa occurred in the early 1990's when a number of people were murdered after they disclosed their status (Skinner & Mfecane, 2004). Other less extreme examples of this include people being dismissed from their places of work or rejected by their communities and sometimes even by family members (Flowers, Davids, Larkin, Church & Marriott, 2011). In some instances children were denied access to schools and some people denied health care access as they were perceived to facing death would die in due course (Dlamini et al., 2008; Skinner & Mfecane, 2004).

### 2.2.3 Associated Stigma

Associated or courtesy stigma is defined as “incidents that describe stigma against people who work or associate with HIV/AIDS associated people, for example spouse, partner, children, friends, family or health care workers” (Greef et al., 2008, p 313). Courtesy stigma is understood as a “social construct rather than a personal attribute” (Birenbaum, 1970). This poses a risk of weakened support to people living with HIV/AIDS as their friends, family or caregivers may withdraw from supporting them as a result of being prejudiced (Herek et al., 1998). In addition, children of PLHA may be discriminated against as a result of their parent’s status (Bougart et al., 2008).

### 2.2.4 Symbolic stigma

Symbolic stigma defined as “the use of AIDS as vehicle for expressing hostility towards other groups that were already stigmatised before the epidemic began” (Herek, 2002, p598). This type of stigmatisation is associated with social meaning attached to HIV/AIDS, which is based on judgmental attitudes towards the “so called” innocent victims and those that contracted the virus through immoral behaviours (Stein, 2003). The moral factor of HIV/AIDS stigma becomes evident due to its relationship to sexual activity; as such, it becomes a symbol of promiscuous behaviour or any unusual sexual behaviours that are seen to pose a risk of disrupting family life (Herek & Capitanio, 1999; Stein, 2003). It functions as a means of maintaining social order by rejecting those that are seen as a threat or appear to possess a certain attribute (Stein, 2003).

What is most evident from these understandings of HIV-related stigma is that it has the potential to negatively shape people’s experiences of being diagnosed and living with HIV.

## 2.3 The trauma of being diagnosed with HIV

Being diagnosed with HIV can be very stressful, due to the uncertainty about the prognosis (Holt et al., 1998; Plattner & Meiring, 2006). An HIV-positive diagnosis can evoke strong emotions, which might cause the HIV-positive individual to become more susceptible to experiencing high levels of stress (Lindner, 2006). These elevated stress levels are not just limited to HIV, but are also common in any chronic illness. However, stress in an HIV positive diagnosis becomes exacerbated by the stigma and discrimination attached to HIV/AIDS (Holt et al., 1998). Moreover, anticipated physical changes, social problems and sexual threats surrounding the diagnosis of HIV infection can make life for those who are HIV-positive very challenging (Lindner, 2006).

There has been some evidence suggesting that the initial emotional responses to the diagnosis can be more devastating than the actual illness, and therefore require a process of psychological adjustment to be able to make meaning of the illness and subsequently cope (Kralik, Brown & Koch, 2001). The trauma of the HIV-positive diagnosis is not only based on fears around threat to the infected individuals, but also extends to the fear of being responsible for unknowingly infecting others (Steven & Doerr, 1997; Plattner & Meiring, 2006).

Previous research has indicated that being from poor or developing countries aggravate the trauma of being diagnosed with HIV infection. Sub-Saharan Africa has been identified as being severely affected by the HIV/AIDS epidemic with women being the most affected group (Jewkes, 2009; Lau & Muula, 2004). Africa has been associated with the continuous change in politics, absence of social stability and poverty (Lau & Muula, 2004). This has even greater impact on women because of their subordinate role in society which makes them more vulnerable to HIV infection and stigma, due to preceding stigmas of gender inequalities and economic dependence (Rohlender & Gibson, 2006; Wingwood et al., 2008).

### 2.3.1 Experiences of being diagnosed

Also prominent amongst the many traumatic events associated with HIV infection is the actual event of receiving the diagnosis. In most cases initial reactions to an HIV-positive diagnosis include shock, which is often associated with denial leading some people to doubt the accuracy of the results (Anderson et al., 2010; Oppenheimer & Bayer, 2007; Stevens & Hildebrandt, 2006). Denial might be prompted by a deep sense of shame due to fear of condemnation by others (Oppenheimer & Bayer, 2007; Stevens & Hildebrandt, 2006).

Other reactions can include a fear of dying, worrying about development of physical symptoms, uncertainties associated to disclosure, fear of being stigmatised, feelings of guilt, suicidal ideation, confusion and anger, despair and hopelessness, feelings of helplessness, anxiety and guilt, sense of great loss of future, disruption in family relationships, reduced opportunities for child-bearing and continuous suffering (Anderson et al., 2010; Groggin et al., 2001; Kelly et al., 2008; Plattner & Meiring, 2006; Stevens & Doerr, 1997; Stevens & Hildebrandt, 2006).

Subsequent to these fears and reactions, HIV-positive people are faced with the difficulty of deciding whether to disclose or not to their families, friends, work colleagues and acquaintances (Holt et al., 1998).

### 2.3.2 Disclosure

The decisions about and the act of disclosure has also been identified as one of the major stressors that faces many people after they have been diagnosed (Holt et al., 1998). People can choose whether they want to disclose or conceal their status and decisions surrounding disclosure are often complicated by the stigma attached to HIV/AIDS (Gilbert & Walker, 2010). However, though often encouraged, choosing whether to disclose can lead to increased stress levels due to its implications on the infected person (Holt et al., 1998). For example, people that choose to disclose are at risk of being rejected and isolated by their loved ones, which becomes even more stressful, but also choosing not to disclose puts the infected individual in danger of practicing unsafe sexual practices and not seeking health care or social support, as well as poor compliance to treatment as they may miss treatment time in order to keep their status a secret (Holt et al., 1998).

Lekganyane and du Plessis (2012) discussed three types of disclosure; firstly, protective disclosure, where an individual will recognizes a person they can trust, where and when they will disclose to that particular person. Spontaneous disclosure is a second form of disclosure is usually unintended and the person that discloses may regret doing as it may have been prompted by anger (Lekganyane & du Plessis, 2012). Lastly preventative disclosure is characterised by the understanding of stigma existence and the person will disclose tactfully in order to avoid discrimination (Lekganyane & du Plessis, 2012).

For women, disclosure is even more crucial because it may determine likelihood of accessing health care (Medley et al., 2009) as they have limited decision making in their well-being due to social restrictions (Medley et al., 2009). For example, for women there are various things to consider after receiving the diagnosis which include fear of rejection (Dagied & Duckert, 2008; Lekganyane & du Plessis, 2012), possibility of failure to secure romantic relationships, and guilt of leaving children should they fall ill or die (Green & Sobo, 2000; Hackl et al., 1997); subsequently leading them to keeping their status a secret (Hackl et al., 1997; Lekganyane & du Plessis, 2012). The feelings of fear have a strong correlation with stigma that is associated with HIV (Lekganyane & du Plessis, 2012; Medley et al., 2009), inevitably leaving the diagnosed person isolated as a way of escaping the anticipated rejection, thus resulting in poor psychological adjustment (Hackl et al., 1997; Medley et al., 2009).

Lower levels of perceived social support may cause people concealing their status out of fear of rejection and disturbance in social relationships (Holt et al., 1998). Most women have fears of disclosing to their partners because they do not know how they will react to the news (Meiberg, Bos, Onya & Schaalma, 2008). As disclosing one's status to partner may lead to being physically and emotionally abused (Fox et al., 2007).

The role of disclosure has been described as twofold; firstly it helps in eliciting support which might enable an individual to gain psychological adjustment and adaptive coping process (Armistead, Morse, Forehand, Morse & Clark, 1998). In addition, when people react positively to the news, relationships with family and loved ones might also improve and become more significant (Varga, Sherman & Jones, 2005). Disclosing one's status can also aid in reducing anxiety and accessing treatment (Gilbert & Walker, 2010). But, secondly, it can also serve as a continuous stressor (Holt et al., 1998). For example, revealing one's HIV status can lead to stigmatisation, discrimination (i.e. rejection and no financial support) and isolating behaviour depriving women the most needed social and material support (Armistead et al., 1998; Varga et al., 2005) and fear of stigma appears to be the main cause for non-disclosure (Gilbert & Walker, 2010), which may lead to poor psychological adjustment and problematic coping strategies (Medley et al., 2009; Wingwood et al., 2008). The way in which this conflict between the benefits and risks of disclosure is typically managed is by partially disclosing the status to those who are likely to be supportive and to those who provide care and treatment while concealing the status from others (Haricharan, 2010).

### 2.3.3 Meaning attached to the HIV diagnosis

As mentioned earlier, a further explanation for the stress of the diagnosis of an HIV infection is the often problematic or unhelpful meaning that is attached to the experience. Such negative self-appraisals are likely in a social context that supports such appraisals (Young, 2011). This may be particularly so because these beliefs are pre-loaded or that people's conscious mental life generally tends to mirror that of socially salient others (Robbins, 2008). According to Moskowitz and Wrubel (2005), "illness appraisals include individuals' understanding of the cause and the consequences of an illness, the interpretation of the symptoms and the meaning that the illness sequelae have on an individual" (p509). These illness appraisals influence the decision making process, which later impacts on health behaviours (Moskowitz & Wrubel, 2005). In addition, the general view about HIV/AIDS is that it is uncontrollable and harmful (Siegel & Schrimshaw, 2005), thus the common appraisal about an HIV-positive result is that a slow and painful death is inevitable (Plattner & Meiring, 2006), and so such appraisals are likely precipitate destructive and fatal behaviours like alcohol abuse and engaging is risky sexual behaviour as a distraction (Kelly et al., 2008).

Ciambrone (2001) argues that that a diagnosis of a chronic illness is a "disruptive experience that affects one's former assumptions and behaviours changes in one's self concept and in the mobilisation of helping networks" (p.518). Due to the stigma attached to HIV and the belief that a positive diagnosis means imminent death can destroy a person's sense of identity (Ciambrone, 2001). Young (2011) stated that "People who are diagnosed with HIV might view themselves in any number of problematic ways that threaten their important life ambitions and the view of the self, including viewing themselves as immoral, frail, deprived and dying" (p. 143). At best, people might believe that their lives hold little future and opportunities for employment and romantic relationships (Groggin et al., 2001). Corresponding emotions include fear, shame, guilt, anger and depression (Young, 2011).

Furthermore, these negative emotions play a major role in developing depression as people may fear rejection, discrimination and even violent attacks, which inevitably reinforces and elevates problematic appraisals (Young, 2011).

Being a chronic condition, the stress and trauma of HIV is associated both with the diagnosis and subsequent living with HIV.

## 2.4 The trauma of living with HIV

### 2.4.1 The impact of stigma and discrimination

Available literature suggests that stigma is an ongoing stressor because HIV infection is perceived as an easily avoided, contagious, immoral and fatal condition (Vanable, Carey, Blair & Littlewood, 2006). Because HIV-positive individuals may anticipate and fear that they will be stigmatised therefore, they might try to conceal their positive status (Gilbert & Walker, 2010). Further implications of stigma and discrimination include social withdrawal (Deacon, 2006); unsafe sexual practices and can also deter individuals from seeking health care or testing (Gilbert & Walker, 2010; Meiberg et al., 2008; Vanable et al., 2006).

Stigma might also influence how people view themselves and subsequently their actions (Deacon, 2006). In addition this stigmatising can lead to poor mental health as it may elevate stress levels and lead to coping difficulties (Vanable et al., 2006).

### 2.4.2 HIV/AIDS and Mental Health

The psychological impact of living with HIV and the associated stigma and discrimination can result in psychopathology (Kelly et al., 2008). One mechanism implicated in the mental disorders that can follow HIV infection is the negative appraisals that people make (Young, 2011). But it is not just that psychopathology is a result of HIV (Freeman et al., 2007): Often people live with undiagnosed and untreated psychopathology that puts them at greater risk of

HIV infection (Brandt, 2009; Collins & Freeman, 2009; Kelly et al., 2008). Substance abuse, for example, has been identified as one of the psychiatric conditions that predispose people to HIV infection (Brandt, 2009; Collins & Freeman, 2009). This is because people are more likely to engage in unprotected sexual intercourse during intoxication, often with a casual sexual partner (Collins & Freeman, 2009; Jewkes, 2009).

Additionally, stigma and discrimination can result in traumatic experiences that confer mental disorders, such as PTSD (Boulind, 2014). Boulind (2014) further suggests that the hypervigilance required for ARV treatment might create vulnerability to the anxiety disorders. Mental health problems in HIV-positive people can also occur as a result of the effects of the virus on the central nervous system or side effects of the treatment (Brandt, 2009; Collins & Freeman, 2009; Kelly et al., 2008). HIV-associated dementia is one of the common side effects of highly active antiretroviral therapy (Collins & Freeman, 2009).

### 2.4.3 Depression

One of the common forms of mental illness associated with HIV is depression (Ostrow & Defranceisco, 1996). Stigma, in particular internal stigma, has also been identified as a contributing factor to the development of depression because stigma supports depressive appraisals to do with loneliness, helplessness and hopelessness about the future (Bartlett & Finkbeiner, 2006; Policy project, 2006). These problematic appraisals may generate stress that may be beyond an individual's ability to cope and subsequently exacerbate depression (Vanable et al., 2006).

Women appear to be the most vulnerable group for developing major depression following an HIV-positive diagnosis (Olley et al., 2004). Many of the women in this study live in adverse circumstances, have a history of distress and difficulties in their work, family or social life like many women (Olley et. al., 2004). Implications of depression also have detrimental physical effects on the HIV-positive individual as immune functioning may be compromised, which might lead to quick progression to AIDS and death (Vanable et al., 2006).

### 2.4.4 Substance abuse

Substance abuse following an HIV-positive diagnosis has also been considered prominent, (Kelly et al., 2008), which might also occur as a result of the initial shock of receiving a positive diagnosis (Freeman et al., 2008). Moreover, people living with HIV/AIDS may use alcohol or substances as way of escaping unpleasant mood states or as a way of avoiding traumatic memories (Young, 2011). However, substance abuse can also lead to high risk sexual behaviour, putting the person at risk of reinfection and various negative social consequences (Freeman et al., 2008). It should also be noted that alcohol consumption in sub-Saharan Africa has long been a way of life for many and has also been identified a major contributor on the spread of HIV/AIDS (Kalichman et al., 2007).

### 2.4.5 Anxiety

Other forms of mental health problems that have been identified in people living with HIV include elevated anxiety, which may be a result of insecurity due to partial medical knowledge and the inability to accurately predict the course of illness (Doyal & Anderson, 2004), therefore a positive diagnosis seems to represent an end of life (Plattner & Meiring, 2006). The uncertainty about how long they have before they start developing physical symptoms and being sick or eventually dying and possibly become dependent on others causes individuals worry (Kalichman & Sikkema, 1994; Plattner & Meiring, 2006). PLWHA also often worry about the people that they may have unknowingly infected before they found out about their status (Plattner & Meiring, 2006). This heightened worry can cause increased sensitivity to threat-related information and an expanded range of possible negative outcomes

(Wells, 1997). In other words, worry may be circular in that the more people worry, the more they have to worry about.

### 2.4.6 Posttraumatic stress disorder

Post-traumatic stress disorder is another mental illness associated with an HIV-positive diagnosis, though whether or not the diagnosis of HIV qualifies as a traumatic event as defined by the diagnostic criteria for PTSD is debated (Seedat et al., 2005). Whether or not there is agreement that traumatic experiences of being diagnosed with HIV/AIDS necessarily meet the criteria of PTSD, various studies suggest that PTSD symptoms are often associated with HIV, including symptoms of intrusion, avoidance, hyper-arousal and numbing (Kelly et al., 2008; Seedat et al., 2005 & Young, 2011). Seedat et al. (2005) state that upon diagnosis people may experience recurrent and intrusive thoughts or dreams the illness or death, which may lead to avoidance of any stimuli that will remind them of the illness. Important, while the diagnosis of HIV can be very traumatic, so too can living with HIV, which can result in severe stigma and discrimination that can result in PTSD in their own right (e.g., Adewuya et al., 2009).

Furthermore, people most at risk for PTSD are people from lower socio-economic backgrounds (Smith et al., 2003), who must cope with an array of other poverty-related stressors, which may serve as a trigger for the development of PTSD. Traumatic events associated with these deprived socio-economic conditions include, amongst other things, homelessness, domestic violence, unemployment, accidents and violent attacks (Smith et al., 2003). In most cases communities and family members tend to distance themselves from people that are infected with HIV because of the perceived life-threatening nature of HIV (Meiberg et al., 2008).

Many of the people living with HIV in South Africa have been exposed to traumatic events in the past (Boulind, 2014), and that PTSD may be as a result of a combination of the events that occur before, during and after the diagnosis (Martin & Kagee, 2011). Indeed, in these situations an effort to identify the index trauma is often pointless (Young, 2011). To alleviate the burden of traumatic stress amongst those most at risk of HIV requires addressing the structural inequalities that put people, especially women, at risk of trauma.

## 2.5 HIV/AIDS and other factors affecting women

### 2.5.1 Gender Inequality

Susceptibility to HIV infection has been recognised to be largely gendered and heightened by gender inequalities (Thomas, 2007). In Sub-Saharan Africa where payment of Lobola is often practiced, women subordination is further reinforced as it encourages men to believe that they own their wives and women in general (Thomas, 2007). Too often women are perceived to be submissive, dependent and inferior, and are expected to obey their husbands' demands for sex even if it is against their own needs (Hoosen & Collins, 2004; Simbayi et al., 2005). Men, on the other hand, are usually perceived to be superior, and have more leadership and decision-making skills (or privileges) in their families and in the community (Thomas, 2007; Hoosen & Collins, 2004). In this patriarchal society, promiscuous behaviour by men is often seen as evidence of being a 'real' man, whereas similar behaviour by a woman is considered immoral (Rohlender & Gibson, 2006).

Indeed, men often view themselves to be naturally superior to women and they often believe that they are culturally entitled to having multiple partners (Leclerc-Madlala, et al., 2009). In certain parts of South Africa there are particular terms such as "isoka" (playboy) or "amakrwala" (initiated men) that are used to endorse promiscuous behaviour (Ngubane, 2010), and such terms might encourage risky behaviour as they are considered complimentary

(Lindegger & Quayle, 2009). Moreover, the belief that men cannot be expected to control their sexual appetite is widespread, thus multiple sexual partners and unprotected sex are perceived to be a norm for masculinity ideals (Ackerman & de Klerk, 2002; Lindegger & Quayle, 2009). Such ideals often leave women even more vulnerable to contracting HIV/AIDS and powerless (Ackerman, & de Klerk, 2002; Dagied & Duckert, 2008).

Furthermore, the practice of polygamy is common in many African countries, which has left a legacy where it is socially acceptable for men to have multiple partners (Ackerman & de Klerk, 2002; Lawson, 1999). Another challenging factor identified by Lawson (1999) is a levirate system which is practiced in many African societies, which suggest that in case of the death of a man in the family a surviving brother should 'inherit' his wife, as she is considered part of the 'property' of the husband.

Moreover, the social interpretation of sex as an expression of love and commitment may be detrimental for women, as they might see their role in sexual relationships as that of satisfying men's sexual needs (Hoosen & Collins, 2004). Such interpretations limit women's ability to protect themselves from HIV infection (Hoosen & Collins, 2004). This may be partly due to men's negative perceptions about condom use as reducing the pleasure of sexual intercourse (Ackerman & de Klerk, 2002). This is compounded by the fact that cultural norms prevent women from being socialised in discussing sex (Leclerc Madlala et al., 2009), thus women insisting on condom usage can sometimes be perceived as culturally inappropriate (Simbayi et al., 2005).

Furthermore, suggestions of condom use by women may become offensive to male and often leads to suspicion about their sexual history and faithfulness in the current relationship (Ackerman & de Klerk, 2002). It might also be interpreted as a form of concealing an STI or undermining the partners 'manliness' (Ackerman & de Klerk, 2002). This can lead to abuse, rejection and abandonment (Ciambrone, 2001; Simbayi et al., 2005) and ultimately lead to loss of financial support (Simbayi et al., 2005).

### 2.5.2 Gender-based violence

Gender-based violence is precipitated by gender inequality and it also serves as a maintaining factor of those inequalities (Jewkes et al., 2010). It has been identified as a global problem (Ackerman & de Klerk, 2002), though South Africa has been reported to have the highest prevalence of gender-based violence in the world (Jewkes, 2009), where violence against women has become a norm for both men and women (Outwater, Abrahams & Campbell, 2005). This stems from the patriarchal nature of society that favours men, who often believe that they are entitled to control women (Jewkes et al., 2010). Men tend to beat up women to ensure that they comply with their sexual needs and to re-enforce their dominance over women (Jewkes, 2009). The point here is that actual or threatened violence creates an environment of male control, which can extend to all aspects of sexual decisions (Jewkes et al., 2010). Violent and controlling men are seen to have an increased HIV risk in women because they create a powerless environment for women. Though rape is frighteningly common, the transmission of HIV during non-consensual sex accounts form only a tiny proportion of the total HIV prevalence; rather it is the control that is enabled by this violent behaviour that is implicated in the high prevalence of HIV (Jewkes et al., 2003).

In addition, violent men also tend to view proposition of condom use as an admission to infidelity or else a means of questioning their own promiscuous behaviour (Jewkes, 2009; Jewkes et al., 2003). Because men have been socialised to dominate women (Hoosen & Collins, 2004), many will use violence as a way of regaining their masculine identity when they feel their power of dominance is threatened (Strebel et al, 2006).

### 2.5.3 Poverty

Previous research has suggested that HIV/AIDS is a symptom of poverty (Lau & Muula, 2004), however in recent times HIV has also emerged as one of the leading causes of poverty especially in developing countries like South Africa (Shisana et al., 2009). HIV/AIDS appears to put people at risk of poverty through loss of income, either through death of a breadwinner, loss of work during periods of illness, or having to leave work to take on caregiving roles to look after ill family members, as well as increased spending on health care (Rodrigo & Rajapakse, 2010; Shisana et al., 2009), which further reduce family income (Smith, 2002). On the other hand people living in poverty-stricken conditions might not worry about engaging in risky sexual behaviour for survival as they may feel they do not have much to lose (Shisana et al., 2009).

Poverty heightens women‘s susceptibility to HIV infection amongst poor women due to poor knowledge and sometimes limited access to the means of protection, which may be as a result of gender inequalities (Booysens & Summerton, 2002). Many women are aware of the risks of unprotected sex but, they might be less likely to negotiate safer sexual practices because they fear losing financial support (Jewkes, 2009). In fact there is some evidence that seems to suggest that condom use is much lower in poorer women, who also tend to have unstable sexual relationships (Booysens & Summerton, 2002; Jewkes, 2009).

Women empowerment is hindered by the unavailability of educational and employment opportunities, thus exacerbating the spread of HIV infection (Rodrigo & Rajapakse, 2010). In addition, lack of employment and poverty deprive many black women of necessary goods such as food and housing, which leads them to move from rural to urban areas for better opportunities (Noble et al., 2004). Even under these barriers, these young women are expected to provide the financial needs of the family that remains in their home villages (Lawson, 1999; Noble et al., 2004).

As a result of such pressures, in many settings sex has generally become to be perceived as a commodity (Jewkes et al., 2003). The likelihood of engaging in transactional sex to obtain material support becomes higher (Rodrigo & Rajapakse, 2010). Transactional sex, involves an expectation of material gain, but unlike prostitution there is no negotiated fee (Jewkes, 2009), even though it has been compared to sex work by many people (Dunkle et al., 2007). However, because its prevalence in the Sub-Saharan African, many women that engage in this behaviour do not perceive themselves as sex workers (Dunkle et al., 2007). The role of transactional sex has been identified as a way of meeting basic survival needs (Dunkle et al., 2007). It is often older men who are employed and have the financial means to benefit from this, which automatically gives them control thus leaving women with no power to negotiate for safe sexual practices (Dunkle et al., 2007; Jewkes, 2009). In addition, this also suggests these older men have had longer sexual histories and more chances of being exposed to HIV, which inevitably place women who engage in transactional sex at risk (Jewkes, 2009).

## 2.6 Coping with HIV

There seems to be evidence suggesting that social support and coping strategies are linked (Friedland et al., 1996). Coping refers to “the thoughts and behaviours used to regulate distress (emotion-focused coping) or manage problem causing distress (problem-focused coping)” (Moskowitz & Wrubel, 2005, p. 510). Social support is defined as “the feeling of being cared for and loved, valued and esteemed, and able to count on others should the need arise” (Friedland et al., 1996, p19).

### 2.6.1 Social Support

Social support has been identified as a significant source in developing adaptive coping strategies (Hinton & Earnest, 2010) and it also helps to combat psychosocial stress (Pergami et al., 1993). Poorer social support is associated with poorer coping skills (Hinton & Earnest, 2010) and even psychiatric problems (Brandt et al., 2006). Available literature suggests that membership of a support group serves as a protective factor against development of a mental disorder (Freeman et al., 2007).

Dagied and Duckert (2008) discussed three types of social support; namely, emotional support, informational support and practical support. They argue that emotional support is "shown through affection and encouragement, which results in a sense of belonging" (Dagied & Duckert, 2008; p.185). Emotional support is usually provided by family and close friends (Lekganyane & du Plessis, 2012); however, it becomes very difficult to attain this if the family relationships are broken and may have detrimental results for psychological well-being (Dagied & Duckert, 2008; Hinton and Earnest, 2008). Informational support, on the other hand, is aimed at educating people that have been diagnosed, in order for them to know and understand what they are dealing with (Dagied & Duckert, 2008). This is because in many cases people diagnosed with HIV usually have inadequate information about the virus, which places them under severe distress that can be followed by depression (Harris & Larsen, 2008). Thus informational support plays a significant role in helping individuals understand and adjust to their diagnosis, especially just after being diagnosed (Friedland et al., 1996). This type of support is usually obtained at the clinics and in support groups (Dagied & Duckert, 2008). Both emotional and informational support play a significant role in combating suicidal thoughts as limited knowledge may prove detrimental to one's health (Dagied & Duckert, 2008). Lastly, practical support which is concerned with assisting PLHIV with day to day requirements (Dagied & Duckert, 2008). It ranges from food parcels to arranging medication and motivating adherence to treatment (Dagied & Duckert, 2008).

### 2.6.2 Coping Strategies

The process of coping is triggered by an appraisal (Maskowitz & Wrubel, 2005): each situation is assessed based on the apparent threat and/or whether the individual will be able to control it or not (Pakenham & Rinaldis, 2001). Thus, if the individual feels that she or he cannot control the threat, he or she may struggle to adjust and cope (Pakenham & Rinaldis, 2001). Newly diagnosed women tend to react with problematic coping strategies (Olley, 2006), which may be at times due to socioeconomic conditions and traditional roles which require women to put the needs of others before their own (Brody et al., 2014; Pergami et al., 1993).

Problematic coping strategies can be both emotional and behavioural and may be unplanned and may be a result of the shock of receiving a positive diagnosis (Anderson et al., 2010; Reeves et al., 1999). The emotion-focused strategies are usually used when the diagnosis is viewed as a major threat that cannot be managed and might be perceived as problematic (Friedland et al., 1996; Myint & Mash, 2008). Their basic function is to deal with the emotions evoked by the infection thus, not aimed at solving the problem which may subsequently lead to poor psychological adjustment (Friedland et al., 1996; Myint & Mash, 2008; Olley, 2009). For example, just after receiving a diagnosis people may cry excessively, feel angry and sad, try and minimise the threat posed by the diagnosis, may blame and isolate themselves and become involved in self-destructive behaviour like abusing alcohol (also known as avoidant coping styles) (Hackl et al.,1997; Myint & Mash, 2008; Olley, 2009; Reeves et al., 1999).

However, not all emotion-focused coping strategies should be considered problematic (Dagied & Duckert, 2008). These include denial, rationalization, spirituality and tradition (Dagied & Duckert, 2008; Olley et al., 2003; Rehle et al., 2008; Siegel & Schrimshaw, 2000). Coping is understood based on context, thus if there are few available resources and disclosure will not necessarily yield any support, using these emotion-focused may be beneficial for the individual living with HIV infection (Dagied & Duckert, 2008).

Green and Sobo (2000) discussed different stages of adjustment. In the adjustment process the diagnosed individual may believe that denying the diagnosis would be the 'best' possible solution, but may also grapple with the consequences that come with denial. Secondly, individuals may find the courage to fight against the illness and it usually when people start looking for adopting practical ways that would help combat the stress of the diagnosis (Green & Sobo, 2000). For example, an individual may start to seek information that about HIV/AIDS in order to limit the uncertainty that is normally associated with a positive diagnosis (Bashers et al., 2004). During this second stage people are mostly able to identify supportive relationships and focus more on strengthening those relationships (Green & Sobo, 2000). However, the socioeconomic conditions of women can hamper this positive involvement due to the fact that they are dependent on a partner for financial support, which may ultimately impede the process of developing adaptive coping (Brody et al., 2014; Green & Sobo, 2000). Lastly, people living with HIV usually develop the will to live even though they understand that their lives are under a threat of being shortened as a result of the diagnosis (Green & Sobo, 2000). Thus, they start to normalise their lives, place more values on things that are considered important and take better care of themselves (Dagied & Duckert, 2008; Green & Sobo, 2000; Olley, 2009).

This evidence suggests that coping strategies may change overtime (Reeves et al., 1999) and become more effective in helping people living with HIV to adjust and cope with their status

(Maskowitz & Wrubel, 2005; Olley, 2006; Reeves et al., 1999). Such strategies may include planning, positive meaning and changing one's way of life, disclosing as well as joining a support group (Olley et al., 2003; Rehle et al., 2008; Siegel & Shrimshaw, 2000).

## 2.7 Conclusion

Much of the literature reviewed here suggests that the diagnosis of HIV is traumatic particularly because of stigma and discrimination. Women appear to be more vulnerable to HIV infection and high levels of stigma, due to other psychosocial factors, including gender inequalities, gender-based violence and poverty. Stigma also seems to impact on psychological adjustment and coping. This appears to increase the likelihood of developing mental disorders for those that are diagnosed with HIV.

# CHAPTER THREE: METHODOLOGY

## 3.1 Introduction

This chapter provides an overview of the research methodology used in this study and the procedure and methods of collecting and analysing the data. Interpretative Phenomenological Approach (IPA) was the methodology used to achieve the aims of the research. The decision to use such qualitative research methodology is explained and justified. Detailed information describing the collection and analysis of the data is provided. Additionally, criteria for the selection of the research participants and the purposive sampling strategy are discussed and justified. Finally, the chapter concludes with a discussion of the validity of the research and the various ethical considerations.

## 3.2 Research Aims

The aim of this research is to explore women's experiences of living with HIV after having been recently diagnosed. Through these lived experiences, the study aims to document the lived experiences and meaning making following a diagnosis of HIV that may be implicated in various problematic psychological reactions. In addition, the study will explore the role of social support in their coping process.

## 3.3 Qualitative Research Design

Qualitative research is considered to be particularly useful for explorative studies (Sandelowski, 2000) because its focal point is to explore how people make sense of their subjective experiences (Hennink, Hutler & Bailey, 2011). This paradigm "offers the researcher the opportunity to develop an idiographic understanding of participants, and what it means to them within their social reality, to live with a particular condition or be in a particular situation" (Biggerstaff & Thompson, 2000, p. 4). This study was therefore conceptualised and conducted within a qualitative research paradigm, as its main aim is to explore how people embody experiences and their actions as they cope with life circumstances (Elliot, et al., 1999). Because this study was aimed at exploring the meanings and understandings made by recently diagnosed women with HIV, it was deemed appropriate to work within a research paradigm that allows participants to provide detailed accounts of how they appraise being HIV positive (Smith & Osborn, 2003), in order to elicit how meaning is made based on the participant's views (Chamberlian, Stephens & Lyons, 2007).

Qualitative research is considered interpretive and open-ended in nature, which allows participants to present a detailed account of their experiences (Smith and Osborn, 2003), based on their contextual influences because these play a crucial role in understanding how meaning is made (Hennink, et al., 2011). It is directly concerned with understanding of experience as it is lived, felt and how meaning is constructed by the participants (Smith & Osborn, 2003). To do this, the qualitative researcher needs to immerse him or herself in the data in order to interpret participants' experiences and actions within context (Neuman, 1997).

## 3.4 Interpretive Phenomenological Analysis (IPA)

IPA is a qualitative approach that is concerned with exploring people's lived experiences (Smith, Flowers & Larkin, 2009). IPA is based upon three central philosophical tenets: phenomenology, hermeneutics and idiography (Shenebourne, 2011). IPA is phenomenological because it is concerned primarily with people's experiences (Smith et al., 2009). The approach is particularly interested in exploring how people assign meaning to their experiences based on their context (Biggerstaff & Thompson, 2008). Therefore, this particular approach is considered suitable when "one is trying to find out how individuals perceive particular situations they are facing and how they make sense of their social and personal world" (Smith & Osborn, 2003, p.55). It is phenomenological in a sense that it requires the researcher to discover hidden meanings in the experience of the participant, thus requiring interpretation to try and find the meaning (Shenebourne, 2011).

IPA considers participants to be experts of their life experiences, yet also claims that the meanings individuals make of different events are best understood by a process of interpretation (Smith et al., 2009). In other words, IPA involves a double hermeneutic where the researcher attempts to make sense of the participant who attempts to make sense of his or her experiences (Smith & Osborne, 2003). This interpretive process is what leads to the understanding of meanings of individuals' cognitive inner world (Biggerstaff, & Thompson, 2008). Therefore, in order to uncover the experience hermeneutics is required (Shenebourne, 2011).

In addition, IPA is considered idiographic because it aims to illuminate detailed insights and understanding from a small number of individuals, preferably a relatively homogenous group of participants in order to be able to comment on convergence and divergence of experiences and meanings, without having to generalise the findings (Conroy, 2003; Smith, & Osborn, 2003). It was "developed to allow rigorous exploration of idiographic subjective experiences, and more specifically, social cognitions" (Biggerstaff & Thompson, 2008, p4). Larkin, Watts and Clifton (2006) further explain that IPA offers first and second order aims of analysis. The aim of the first order analysis is to produce a logical psychologically informed third party description of the participants' experience. The aim of the second order interpretation is to position the participants' description into a broader social, cultural and theoretical context (Larkin, et al., 2006).

IPA is said to mediate the opposing positions of social cognition, the dominant approach in health psychology, and the emerging challenge to this offered by discourse analysis: while IPA retains commitment to cognition, it also emphasises the role of context and language in shaping people's lived experiences (Smith, 1996).

### 3.4.1 Limitations of IPA

IPA considers the role of language as important because it shapes experiences and the way the participants express themselves to the researcher (Willig, 2001). This notion is based on the belief that the participants will be able to express themselves and convey their experiences to the researcher, which is debated (Willig, 2001). A further limitation identified by Willig (2001) is that IPA focuses on describing the lived experiences of individuals, rather than trying to explain them. Smith et al., (2009) acknowledge that much IPA research emphasises good descriptive understandings, but also that understandings that participants may be unwilling or unable to recognise themselves can contribute to a more complete understanding of the participant's experience. Both levels of interpretation can be incorporated in IPA.

### 3.4.2 Sampling

As indicated, IPA is an idiographic approach, which favours small samples that allow for in-depth analysis (Smith, 2004), since attempts to analyse the transcripts of large samples may lose the rich meaning (Brocki & Wearden, 2006). The general guide for student projects using IPA is three to six participants (Smith, et al., 2009). In addition, homogenous samples are considered suitable for an IPA study as they that are able to provide rich and significant data about a particular shared experience (Smith et al., 2009). Therefore, this study consisted of five Black females from Jabez HIV/AIDS Centre in Joza Township, Grahamstown. They were between the ages of 26-33. Three of the participants were already on ARV medicines. Only two participants were employed and the rest were dependent on significant others for financial support. Their level of education ranged between Grades three and Matric.

Inclusion criteria was that all participants should be HIV positive and should be18 years of age or older. They had to be isiXhosa speaking and had been diagnosed with HIV between 2-24 months. Two months and two years was considered because people might have started making sense of the diagnosis and could give rich data as it considered a crucial period for going through the emotions, meaning making and psychological adjustment. The proficiency in isiXhosa was due to the fact that there are few studies that have been conducted in isiXhosa and also to provide the participants with an opportunity to fully engage with the researcher about their experiences of living with HIV and what it means to them to be living with the virus and subsequently how they cope with the diagnosis

### 3.4.3 Data collection

Semi-structured interviews are considered the most suitable way of obtaining data within the IPA approach (Smith & Osborn, 2003). Semi-structured interviews are sufficiently flexible to allow for the emergence of unexpected data while also ensuring that all the important areas are covered (Brocki & Wearden, 2006). Interview questions were designed to elicit how the participants understand and make sense of their diagnosis, and subsequently how they view themselves following an HIV positive diagnosis. Also central to IPA is that the interview is seen as collaborative process, highlighting that participants are experts in their stories (Brocki & Wearden, 2006). Thus the interview schedule (see appendix C) was used as a guide about the main themes for discussion (Biggerstaff & Thompson, 2008). The participants were motivated to give detailed account of their experiences, thoughts and emotions and probes were used when clarity was required.

All interviews were done individually at the Jabez Centre at a time convenient to each participant. The interviews were conducted in isiXhosa, which is the home language of the participants in order to ensure they were able express themselves in the best possible way. All the interviews were audio-taped to ensure accuracy and the principal researcher transcribed these recordings verbatim, consistent with the requirements of the IPA (Smith & Osborne, 2003). Once transcribed, the transcripts were then translated into English by the principal researcher for analysis. The researcher tried to translate the transcripts as closest to what the participants had said. Transcripts were translated into English for the purposes of supervision and the dissemination of the results.

### 3.4.4 Data Analysis

Consistent with the idiographic nature of IPA each interview transcript was analysed individually before looking at convergence and divergence of themes across the cases (Smith, 2004). The first order analysis was used in order to generate a logical psychologically informed third party description of the participants' experience. The aim of the second order interpretation was to position the participants' description into a broader social, cultural and theoretical context (Smith, 2004). The IPA analysis emphasises on examining each transcript for themes and building connections between these themes, before moving on to other transcripts and repeating this process with each, finally identifying specific themes (Reid, Flowers & Larkin, 2005).

Smith & Osborn (2003) provide a step by step process on how to analyse data. The first step includes reading and re-reading, which allows the researcher to become immersed with the transcripts to in order to gain a deeper understanding of the content and the participants experiences (Smith & Osborn, 2003). In addition, during this step it was important to note anything of interest particularly, thoughts, emotions and language used (Biggerstaff & Thompson, 2008). During this step the researcher took note of appraisals made by women subsequent to the HIV positive diagnosis. The second step involves developing emergent themes, which entails identifying themes that come up in the data and that would mainly describe the fundamental aspects of that particular interview (Smith & Osborn, 2003; Biggerstaff & Thompson, 2008). Moreover, the researcher searched for connections across emergent themes, looking at how themes relate to each other. At this stage fundamental themes consisting of how appraisals were made, emerged. It is noteworthy that, in qualitative research there may be novel information, which may require the researcher to argue for a different theme (Biggerstaff & Thompson, 2008). However, contrasting themes can only be identified once the researcher has re-visited previous transcripts to see whether important information could have been missed (Biggerstaff & Thompson, 2008).

The third step involves clustering of themes, discovering group themes with which the aim is to identify super-ordinate themes (Biggerstaff & Thompson, 2008). The structure of these higher order themes was also cross-checked in all the transcripts. The fourth step of the analysis involves a development of a summary table of the identified themes and the table should be organised in a way that clearly illustrates the main aspects and concerns recognized by the participants (Biggerstaff & Thompson, 2008). This step allows for use of examples from the participants, which can include direct quotations from the participants' accounts that provide fundamental features of the participants thoughts and emotions about the experience of the situation being explored (Smith & Osborn, 2003; Biggerstaff & Thompson, 2008). This process of analysis continued as the researcher moved on to the next case and looking for patterns across cases, which basically meant going through the same process until all transcripts were analysed. In writing up, attention was paid to details that demonstrate the ways in which the women in the study view themselves and their situations after the HIV positive diagnosis (Smith & Osborn, 2003).

## 3.5 Validity

Yardley's criteria on how to assess validity was used to ensure the validity of this study (Smith & Osborn, 2003). The first principle involves *sensitivity to context*, which was done by means of looking at the existing literature on this topic and comparing it with the data collected from the participants (Yardley, 2000). Furthermore, cultural context observations done during interviews and ethical issues are also indicators of sensitivity to context (Yardley, 2000). Reflexivity in qualitative research is highlighted as one of the important aspects in qualitative research, due to the belief that all researchers enter the field of research with preconceptions of what they are exploring. The researcher had to constantly reflect in terms of how questions were posed and the reasoning behind asking them. Though it should be noted here that IPA does not require people to bracket off their knowledge and experiences, but rather acknowledges that the final product of the research endeavour is the researcher's attempt to make meaning of the participants' variety of experiences (Smith et al., 2009).

The second principle addresses *commitment and rigour*, whereby the researcher is committed to understanding the phenomenon that she is studying from the viewpoint of the participants (Smith & Osborn, 2003). The aim was to obtain the story from the participants, as it is experienced by them, which included verbatim quotes from the data in order to keep to the participants' perspectives (Yardley, 2000).

Thirdly, *transparency and coherence,* which is about the description of each stage of the research process as a way of illustrating transparency (Smith et al., 2009). This principle also deals with the presentation of data in a logical way (Shenebourne, 2011) and whether the methodology used to answer the question is suitable (Yardley, 2000).

Lastly, fourth principle of *impact and importance* looks at whether the qualitative research project is significant and useful (Smith et al., 2009). The real validity of a research project is based on whether the project has something important, interesting or valuable to bring to light (Yardley, 2000). In this regard, this is one of only a very few studies that explores people's lived experience of the diagnosis and subsequent living with HIV by interviewing participants in their first language. Monolingual isiXhosa speakers are often excluded from such research because such research interviews are typically conducted in English.

## 3.6 Ethical Considerations

Ethical approval and permission to conduct this study was provided by the Psychology Department's Research proposal and ethical review Committee (RPERC) (the letter giving such approval is attached). Additionally, the proposal was approved by the Humanities Higher Degrees Committee.

The targeted sample was considered vulnerable, who might become distressed by some of the questions asked of them. According to Orb, Eisenhauer and Wynaden (2004) research participants should be given the genuine facts about the research experience before they can be asked whether they would agree to participate. Therefore, the participants in this study were informed about the nature of the study, what is required from them and how it could possibly affect them after the actual interview. In addition, it was explained to the participants that participation is voluntary and they were informed about their right to withdraw from participation at any time should they feel uncomfortable. Moreover, it was also explained that withdrawing or refusing to participate would not affect their relationship with Jabez Centre or with the Care Worker in any way. Informed consent was then obtained from each participant and anonymity was guaranteed throughout the study. Moreover, the researcher also made a provision for anticipated distress during or after interviews to contain the participants and subsequently refer them back to the Jabez Centre and to the Care Worker involved.

## 3.7 Conclusion

This chapter presents the method of research methods used in this study in order to meet the aims of the study, which is to explore how women that have been recently diagnosed with HIV make meaning of their diagnosis. This was done by using Interpretive Phenomenological approach (IPA), which includes the process of data analysis which will be demonstrated in the next chapter. Ethical considerations relevant to the study were addressed as well as issues of validity of the study.

# CHAPTER FOUR: FINDINGS AND DISCUSSIONS

## 4.1 Introduction

This chapter presents and discusses the findings of the study. There were five themes that emerged namely, *experience of receiving a HIV-positive diagnosis, Stigma experience, Social Support, coping strategies, HIV/AIDS as one of many 'insults'.* These themes come from the participants realities about how being diagnosed and living with HIV has impacted their lives.

## 4.2 Participants

Participants in this study were five Black, isiXhosa speaking women from Jabez Centre in Grahamstown, an NGO that supports HIV positive people. All five participants were HIV-positive and they had known about their status for at least two months and no longer than two and a half years at the time of interviews. The following pseudonyms were given to the participants to ensure that anonymity is maintained; Nandi, Lakhe, Lihle, Sino & Noni. Nandi and Lakhe are both employed and have one child each. Noni also has one child and she is unemployed. Sino is unemployed and she had one child who died at infancy. Lihle is employed and has no children.

## 4.3 Findings

There were five themes that emerged from the data. The first theme that was identified was the *experience of receiving a HIV-positive diagnosis*. This theme is concerned with the initial reactions to the diagnosis. As expected testing for HIV/AIDS can evoke various emotions because of how it has been preconceived. Thus, this theme highlights the emotions felt after being diagnosed and the meaning that the women in the study attach to the positive diagnosis. The second theme is about *Stigma experience,* which includes the consequences of stigma on the women's lives. The third theme is that of *Social Support* which describes the value of support and how it contributes to psychological adjustment and subsequently helps the women to cope with the HIV positive diagnosis and the stigma attached to it. The fourth theme has to do with *coping strategies* used by women following an HIV positive diagnosis. The fifth and final theme is that of a view of *HIV/AIDS as one of many 'insults'* in life, which suggests that for most women in this study testing HIV positive might not be the most tragic experience that they have had to go through in their lives. Thus testing positive for HIV might not on its own be appraised in such a way that would necessarily be deleterious to their mental health because it is often just one of many adversities that these participants have experienced in their lives. It should be noted that some of the themes overlap, but each will be discussed separately.

## 4.4 Discussion

### 4.4.1 Theme 1: Experience of receiving a HIV-positive diagnosis

#### *4.4.1.1 Reasons for getting an HIV test*

People have various reasons for seeking a HIV test; in some cases people are simply offered VCT when they go to health care centres, while others may want to go because they may be experiencing symptoms or they may seek an HIV test following a partner's disclosure of testing HIV positive. However, most people may avoid getting tested because they fear the outcome of the result will be that they are HIV-positive (Gilbert & Walker, 2010). For most women testing becomes unavoidable when they fall pregnant as it is a routine part of the prevention of mother to child transmission (Varga et al., 2005). The women in this study described a variety of reasons that influenced them to seek HIV testing.

For Sino and Lakhe testing for HIV was a routine aspect of their pre-natal care routine that has been established to prevent mother to child transmission (PMTCT):

> *When I fell pregnant, you know you have to go for those monthly visits to the clinic so I was tested and they told me that I was positive* (Sino).

Similarly, Lakhe found out that she was HIV-positive when she was pregnant, though it seems that her initial response was one of denial:

> *I first found out in 2011 when I was pregnant, but I ignored that. I did not do any follow up after I gave birth. Then I went back late last year to test again* (Lakhe).

In contrast, for Nandi, testing was offered by a health care provider when seeking treatment for flu symptoms, though possibly it was these symptoms that prompted the healthcare provider to suggest the testing:

> *I went to Johannesburg to visit my older sister and to look for work, so I had flu and then I went to the clinic so they offered me VCT so I agreed and I confidently said "you can test me I don't have a problem" so I tested and they told me that I tested positive* (Nandi).

Interestingly, for the three participants just mentioned, an HIV-positive diagnosis was received while seeking healthcare seemingly unrelated to their HIV status. What it suggests, certainly in Nandi's case, is that the diagnosis often comes as a complete surprise.

For many others, testing is prompted by learning about their partners' positive status, which would cause them to contemplate the possibility that they themselves might be HIV-positive before even engaging with health providers (Sethosa & Peltzer, 2005).

Noni tested for HIV because her boyfriend became sick and was admitted to hospital. He then disclosed to her that he had been diagnosed with HIV, prompting her to consider her risk and seek an HIV test. While Noni seemed aware that her boyfriend's health could mean that she too was HIV-positive, it is unfortunate that she could not have predicted or avoided this possibility before she became infected.

> *I tested in 2012 I was still staying at home and I was dating someone else not the father of my child because he went to prison so I met somebody else. He became sick sometime mid-year so I used to visit him in hospital. I was visiting everyday so he told me that I should go and test because he was told that he is HIV-positive, so I went and tested the same day and I also tested positive* (Noni).

Lihle's reasons for getting tested were very different to those of the other women. She reported testing at a youth camp as a way of trying to raise interest and encourage testing among peers. This was because she worked for Love Life and she wanted to lead by an example, but she had not anticipated an HIV positive result.

> *It was in ....2011 at the end of the year camp and we went to Jeffrey's Bay. We had a camp organized by love life so as part of creating awareness they were testing people there at the camp. There were also other basketball teams that were there and I was also groundbreaker for Love life. We arrived at the camp on Friday night and then on Saturday Love life had a VCT drive and we thought we should lead by an example and go and show others the importance of testing, so I tested bit they did not give us the results until we got back in Grahamstown....and……. we came back from camp on Sunday afternoon you see and then next thing on Monday I received a call that I should go to the office. I am not going to lie I had no clue why they would want me to go the on Monday because I meet my peer group on Wednesdays, so I just thought to myself I will find out when I get there. When I got there the lady that tested me at camp was there and Coach was there so they just said the reason they did not give us the results it is because I tested positive at camp* (Lihle).

It is evident from these accounts that individuals have different reasons for testing for HIV, though what is common for all, apart from Noni, is that they did not appear to seek an HIV tests because they believed that they were at risk. That only one of the five considered herself to be at risk seems to be in contrast with the HIV prevalence statistics for pregnant women, where 30.2% of pregnant women between the ages of 15 and 49 were living with HIV in 2010 (Department of Health, 2011).

Though Lakhe describes that despite knowledge of the impact of HIV on others, she still thought that it would not happen to her:

> *In reality you see you hear about HIV/AIDS and you know it is there but you just never think it can happen to you. Yes I knew that it is a virus that is out there, but I did not know what it is exactly, you see. So I just thought well if I have it will come out and I will see then* (Lakhe).

One of the functions of stigma is to allow people to manage their fear by distancing or 'othering' themselves from those who are HIV positive, which may sustain the belief by some that it cannot happen to them (Howard-Payne, 2010). This was also described by Lapinski, Ramil, Klein and Shulman (2009) as 'optimistic bias', which basically suggests that people might view risk to infection through comparing themselves with others who are perceived to be 'deviant'. This helps individuals to develop a false sense of security (Howard-Payne, 2010), which might at least partly explain why the women in the study were surprised by the results.

#### 4.4.1.2 *"like someone had hit me with a brick on my head": Reaction to the diagnosis*

Because an HIV-positive diagnosis signals stigma, discrimination and thoughts of a premature death might evoke strong emotions (Plattner & Meiring, 2006). This was certainly true of the participants in this study, as they reported feelings of shock and some experienced confusion, disbelief, denial, anger, and suicidal thoughts.

Because Lihle did not anticipate the possibility of a positive result, her reaction was one of shock and confusion:

> *Look sisi, I did not expect to test positive I mean I did not even worry when they said we are not getting results, the worst part I did not even relate the call to the camp so when they told me I had tested HIV positive…I was so shocked and confused* (Lihle).

Neither did Nandi anticipate the positive outcome of her test:

> *I was so shocked because I was not expecting a positive result that the results would be like that* (Nandi)

Even Noni, who sought testing after her boyfriend disclosed his HIV status to her, did not expect to test positive. Again, she was shocked and could not initially tell people of the result of the test:

> *I was in pain I was not expecting to test positive. I was very shocked and they spoke to me trying to comfort me and I left but when I got home I did not tell anyone* (Noni).

For some people when they test positive feel the need to seek a second opinion because they may be questioning the accuracy of the results and, understandably, hoping for a different result (Oppenheimer & Bayer, 2007). Lakhe tested HIV positive when she was pregnant, but did not accept the diagnosis to be true. When she tested for the second time she describes feeling shocked as she had hope that the second results would be negative even though she had tried to prepare herself emotionally for the second test.

> *I was shocked even though I was trying to calm myself down when I was going to the clinic and even when I was waiting for the results because I was trying to convince myself that even if the results come out positive it is something I have heard before, but when the results came out I was shocked…..(becomes tearful) anyway I think I was more scared than shocked and I cried, but the lady at the clinic said "no sisi you are a mother, what will your child do if you are crying like this how do you think your child will feel?" so I thought "oh my God this woman is right" so I wiped my tears* (Lakhe).

Lihle describes how she struggled to believe what she was being told that she had tested positive:

> *At first I thought I did not hear what they had just told me. I remember just sitting there looking at them I wanted to ask questions but the words were just not coming out of my mouth……. I don't know I wanted to get out of that room because I did not know what else to do. I wanted to ask questions but I did not have the questions my mind was just racing and I literally could not speak, I seriously thought it was just a bad joke seriously like a very bad joke, but ja they were serious……I thought "it is a prank" they will tell me that they are joking* (Lihle).

Lihle went to describe feeling blank, numb and unable to express herself after she received a diagnosis:

> *I just froze. Look, just imagine this you test and you are not even serious about this testing thing, then they spin you a story about why you're not getting the results and then you forget that you tested and then they tell you something like this, just imagine! …….. and then I am like no no and I think I just went blank because thoughts were just rushing through my head to a point where I would not have been able to answer if*

> *somebody had asked me what I was thinking.....Worst day of my life sisi. It was like someone had hit me with a brick on my head, I felt numb (*Lihle).

Nandi reports feeling angry towards her partner after receiving the diagnosis, which is a common feeling experienced by most people after receiving an HIV positive diagnosis (Bartlett & Finkbeiner, 2006):

> *I hated myself and I was also angry towards my boyfriend since I thought he might be the one who infected me because, I was not promiscuous so that is why I had that anger towards him. Yes he was not my first, I had other boyfriends before him but when I got in Joburg and I met him. I was very angry, but I tried consoling myself by saying I already have it so I consoled myself and I thought being angry is not going to change anything* (Nandi).

Lihle's anger was more directed at herself. In the following except she explains this some more:

> *Maybe I was more angry at myself. I worked for Love Life I should have known better because I was preaching the ABC but I did not apply it to my life so I had lots of questions I could not answer, regrets and so on.....I think after I started realising that this was not a joke and it was not going away I started becoming very grumpy, I was just always angry I did not want to be around people* (Lihle).

Lihle blames herself for not practicing what she 'preaches'. Her mood changed and she became socially withdrawn with the realization that her HIV status is permanent. Cognitive models of HIV-related psychopathology suggest it is the negative appraisals of one's HIV status that can result in chronic negative mood states (e.g., Young, 2011).

The reaction to receiving a diagnosis of being HIV positive includes suicidal ideation. Suicide can be seen as a way of escaping the uncertainty that comes with living with HIV (Bartlett & Finkbeiner, 2006).

> *I had days where I just wanted to end my life; this was before I came to the Centre the thought would just cross my mind. After I found out it was all I could think about like every day* (Nandi).

> *I thought what should I do, should I kill myself or what and I thought about suicide every day, as a result even if I am sitting with people I would just drift away and not hear anything* (Sino).

Lakhe and Nandi related their experiences of thinking that they would die sooner than they had expected to live. Lakhe was sick when she tested, which is why she immediately assumed she was dying. Nandi also thought that being diagnosed equals death.

> *I thought (pause) about what was going to happen and I wondered if the blisters were a sign that I am dying, because the pain I felt when I had those things was just too much, so I thought that I was on my way out* (Lakhe).

> *As I was already told that I have it, I thought to myself yhoo I am going to die soon and I am going to leave my child behind* (Nandi).

For Noni the fear of death associated to her diagnosis was evoked by seeing her boyfriend sick and eventually dying and when she was diagnosed her immediate thoughts were that she was going to die soon.

> *I am not going to lie I was shocked when I heard he died and I thought maybe I would also die soon, but I did not worry much because I was not sick I am not sick even now*

> *so I didn't think much about that. I thought was going to die sooner than I expected* (Noni).

Some of the women reacted with passivity and might have felt they had no other option but to accept their status:

> *I just told myself that I will do whatever the doctors are telling me to do, if they are telling me to take medication or pills I will listen. I was told that there is a chance that the child can be infected or maybe not, so I listened to whatever I was told because I did not want my child to be sick* (Sino).

> *I just told myself that I am HIV positive and there is nothing I can do to change that so I just need to move on and carry on with life* (Noni).

None of the women anticipated a positive HIV test result, which is likely to have contributed to their sense of shock and disbelief on being informed of their results. All of the women in the study were sexually active, but it appears that they never thought they could get infected. This appears to support the previous research findings of 'othering' by Howard-Payne (2010). Other reactions included social withdrawal and suicidal ideation in the expectation that their lives would be cut short, while others took a passive attitude towards the diagnosis, which could also suggest some sense of 'mental defeat'.

#### *4.4.1.3 Meaning of the HIV positive diagnosis*

The general view about HIV/AIDS is that it is uncontrollable and harmful (Siegel & Schrimshaw, 2005). "People who are diagnosed with HIV might view themselves in any number of problematic ways, including as immoral, frail, deprived and dying, that threaten their important life ambitions" (Young, 2011, p143). Important life ambitions for women that are threatened include the chances of becoming a mother, the increased possibility of an end of friendships and romantic relationships and support from family (Sanders, 2008; Plattner & Meiring, 2006).

For Lihle testing HIV positive meant to her that she will never have children as she considers it an irresponsible thing to do and might have negative effect on her health:

> *I am a lively person by nature and I always wanted to get married and have children, so when I was starting to come to terms with my diagnosis I used to think about those things. Ok, like I know that they say you can still have children and all but there are no guarantees so I don't think I want to bring children on earth only to leave them. I have seen people that were healthy had children and after that CD4 count drops, what what…so even if you are sick and you are going to recover in time who is going to take care of you and your baby? I was not responsible enough to protect myself, but I can be responsible enough not to bring children into a situation that I know I might not cope with* (Lihle).

Lihle also explained how difficult it is to find a romantic partner when an individual is HIV positive because it raises the issue of when and how to disclose being HIV positive to that person:

> *When I meet a guy, especially if I like him, I have to think about whether I want to disclose to him or not, when, you see that, if I do will he stay with me or walk away…..you see; which is something you or any other girl who is not positive will not go through. Now does that mean I am not going to date? It doesn't it's just means that with me there is much more to consider…if that makes sense* (Lihle).

For Sino becoming HIV positive means ill health as she feels it has made her frail as she has had to be admitted to hospital repeatedly since she her diagnosis.

> *My life has changed I am in and out if hospital now, I am sick I cannot eat everything I want like I sometimes only eat movite in the morning I cannot eat any other cereal because I will vomit. I cannot eat spicy food as well; I get heartburn if I eat spicy food. Yes I never used to be in and out the hospital like this, even when I got sick when I was working at the farm that was the first time (Sino).*

This theme discussed the participants experiences of receiving a diagnoses, including their reactions and appraisals. What does stand out is that all the women in the study were surprised by the results even though they appear to have been engaging in unprotected sex. Additionally, even with the wide knowledge of available treatment the participant still thought they would die as a result if being diagnosed with HIV. The following theme discusses stigma.

### 4.4.2 Theme 2: Stigma

#### *4.4. 2.1 Experiences of stigma*

HIV/AIDS is a highly stigmatized illness due to factors associated with the perception that it is contagious, life threatening, sexually transmitted and associated with marginalised, ‘deviant’ groups (Meiberg et al., 2008). Stigma becomes a major barrier to testing and seeking treatment and is thus a barrier to a healthy process of adjustment to the illness (Gilbert & Walker, 2010, Meiberg et al., 2008). The stigmatising attitudes leave people living with HIV with little choice but to conceal their status or isolate themselves as they fear discrimination. Discrimination in this context refers to the actual acts of stigma directed towards people living with HIV/AIDS. Even though there is evidence that suggests stigma has declined over time, it is still a continuous problem for women with low socioeconomic status (Stein, 2003; Kalichman et al., 2009). The women in this study had also experienced stigma from family members, friends and from people in their communities.

Nandi described how her brother acted towards her based on suspicion that she might be HIV positive:

> *My late brother stigmatised me, very strange ke I never disclosed to him because I knew he likes to shout at people when he is drunk so I knew he would use that, but maybe with the weight he may have suspected it ooh and I think he saw that I was taking pills and put two and two together, but I did not care* (Nandi).

For Noni people in her community would gossip about her after they had heard family members shouting her about her status. People often seem to say things to her that are humiliating and hurtful, and ultimately deeply alienating. The stigma at times would not be directed to her, but her son. This is known as courtesy stigma and also one of the reasons people conceal their status in order to protect their children from being stigmatised (Bougart et al., 2008).

> *I am not always at home I move around a lot, but if I am there even for a week if I do something they do not like and then they swear at me like for example "no wonder you got AIDS". No they will gossip like if I dress up they will say things like "shame some dress up and pretend like they don't have this thing" but I know it is coming to me because I don't usually care about how I look because I am always drunk anyway. Sometimes they say things to my son, like no one ever came up to me, but they will say to my son "your mother is like this and like that" maybe when they have a fight on the street and that child's mother will shout at my child and say "you are going to be like your mother and have bad habits like her" something like that; which is a same thing that my aunt is doing saying things like "you will just be like your mother and bring diseases to his home* (Noni).

This is Sino's account of being discriminated against by her mother and she also points out how it made her relationship with her mother even worse than it was before her mother learned about Sino's status.

> *It was after she heard, she was in partnership with my sister because my sister was getting a grant and they would not give me anything. I would say it became worse after she found out about my status because she would stand on the street shouting at me, the other day a man from the community called her and reprimanded her for what she was doing. She ended up staying with man because he was buying her alcohol and would send sour milk for us because he had cows. My mother would come home around midnight and wake me up and start swearing at me about my status and the fact that I have a child* (Sino).

Lihle reported that her sister wanted her to be isolated from the family, because she feared being infected.

> *They understood for a while and then my sister suggested that I should move to a back room just to give me space and that they would put a TV there for me and what not; and I thought 'great idea' because I did not want to be around them as well, but I did not realise that my sister was doing this because she was not comfortable with my status so the idea was not about me* (Lihle).

What these excerpts reveal is that stigma comes not only from distant members of the community but also from people's families – the very people that many would expect to provide support and protection.

Lihle also lost her long-term friend after she disclosed her status to her:

> *Yhooo sisi, it is true what they say about you see your true friends when you are in trouble my closest friend avoided me since then and until today. We are no longer friends because of my status even if we meet on the street it becomes awkward* (Lihle).

These excerpts reveal that those who are diagnosed with HIV face rejection and abuse, and can be deprived of opportunities for social support.

#### *4.4.2.2 Consequences of Stigma*

Social withdrawal is the common way of dealing with stigma for many people living with HIV (Dagied & Duckert, 2008; Lekganyane & du Plessis, 2012; Steven & Hildebrandt, 2006). It serves as way of protecting self from discrimination and the condemnation that comes with HIV (Dagied & Duckert, 2008; Walker & Gilbert, 2010). Consequences of stigma may lead to individuals concealing their status and may end up suffering in silence (Skinner & Mfecane, 2004). Women in this study also described a combination of factors that were triggered by fear of stigma.

For instance Nandi would lock herself in her room just to avoid contact with people because she did not want to explain herself to people.

> *For the first two months I am sure that I used to feel like this almost every day. I wanted to be alone all the time I did not want people around me, I was thinking about this thing* (Nandi).

Sino had also experienced stigma after disclosing her status to her biological mother and sister and when she was taken in by her aunt she did not want to disclose as she feared that she would be discriminated all over again. She added that she did not want people gossiping about her and anticipated that is what the people would do should they find out that she is HIV positive. She reveals that she manages the conflicting need to disclose to obtain social support and the need to avoid stigma and discrimination by partially disclosing her status. Partial disclosure is the typical form of disclosure that some individuals living with HIV/AIDS use to protect themselves from stigma and discrimination as it allows them to only share their status with a selective few (Haricharan, 2010).

> *I think they found out this year. They had to know because I was sick otherwise I never told them anything before that. They only found out when I started being involved with the volunteers, in fact the volunteers told them. I asked the volunteers to tell them. I have only told one girl, the one that I go with to the clinic and she has been very supportive because she also has HIV, and the people that I live with now know I told them. Otherwise I do not speak about my status openly because the people skey (gossiping). They gossip about you, like another woman who lives in this area as well she told people about her HIV status and they were always laughing at her and talking about her, so I do not want that. The guy that I am dating now also knows my status because he saw my clinic card and I also told him that you know that I go to the clinic and this is how they see me* (Sino).

Lakhe's preference is to refrain from telling people that she is HIV-positive:

> *I think my status is nobody else's business and I am not going to lie to you I don't have a problem with anyone because here I am I don't have sores I don't have any symptoms even if a person can act strangely towards me and try and distance themselves from me because they see me at the clinic, it is not like what I they will automatically have what I have* (Lakhe).

A fear of stigma appeared to have been a major and legitimate concern for the women in this study to an extent that they opted for partial disclosure as a protective measure against stigma and discrimination. This seems to be the best way of managing the risk of receiving stigma with the need to access social support, which is discussed further in the theme below.

### 4.4.3 Theme 3: Social Support

#### *4.4.3.1 Disclosure and Support*

As discussed above, the main reason that people are reluctant to disclose their status is their fear of stigma. On the other hand, as mentioned, disclosure is considered to be necessary to elicit social support (Lekganyane & du Plessis, 2011). Thus reasons to disclose include seeking support and empathy, and to negotiate safer sex practices in order to avoid re-infection and prevent the infection of others (Meiberg et al., 2008).

Receiving support from family and friends has been associated with positive psychological adjustment and more adaptive coping strategies (Freeman et al., 2007). Family usually provides the individual living with HIV with emotional support, which makes them feel loved, understood and valued (Medley et al., 2009; Friedland et al., 1996). Poorer social support is associated with poorer coping skills (Hinton & Earnest, 2010) and even psychiatric problems (Brandt et al., 2006).

> *I think I said my sister and my mother's support played a major role because they were always motivating me so at least I saw that I was not alone (*Nandi).

> *We spoke and I explained to her (mom) what happened and I will not lie she supported me since then* (Lihle).

Sino felt very welcomed by her aunt, which caused her to question the way her mother treated her:

> *Yes. They don't complain here I feel very welcomed… I don't know the way my aunt treats me feels like the way that my own mother was supposed to treat me* (Sino).

Noni felt she was not even entitled to feel her emotions, but was forced to accept her status and move on because no one cares enough to support her.

> *Who am I going to speak to about those things? Maybe if my mother was around things would be different, but now if I don't pull myself together and remain strong no one is going to encourage me* (Noni).

According to Nandi she disclosed to her family because she wanted support and understanding and her mother and sister were very supportive towards her. She describes her mother's response when she disclosed her status to her.

> *Yes it was immediately after she heard, after I told her she just said re-assured me that I would be fine saying all those things like diseases are meant for people and so on and she actually said she had noticed that I was not the same person I was before leaving home, she said she had noticed that something was bothering me and I also felt relieved that she was understanding* (Nandi).

She went on to say:

> *I told my family and they welcomed me my sister works in Joburg so I had already told my sister while I was still there and she did not have a problem and when I got back this side I told my mother and she also accepted me she said to me 'this is a disease and it meant for people' so I ended up feeling ok* (Nandi).

Social support is very important. But the acceptance that her family gave her is important in another way: As noted, implicated in the psychological problems that can result from receiving a diagnosis of HIV are various negative self-appraisals that people adopt (Young, 2011). Being treated by family members in an accepting way refutes any lingering self-appraisals that she rendered unacceptable to others by the virus.

Similarly, the support that she received from her family ensured that she did not need to appraise herself as being alone:

> *I think I said my sister and my mother's support played a major role because they were always motivating me so at least I saw that I was not alone (*Nandi).

In contrast, negative relationships make it harder for an individual to access support from family (Dagied & Duckert, 2008), as negative relationship can be unsympathetic and challenging which has detrimental results for well-being (Hinton & Earnest, 2010).

Noni's circumstances are very different to those who can count on their families, and she lacks any social support:

> *No I don't have any support because even the lady, I mean the aunt from across the road does not know my whole story like I have only disclosed my status to her and she also know that I have a child; anything else she does not know* (Noni).

She can count only on herself:

> *Who am I going to speak to about those things? Maybe if my mother was around things would be different, but now if I don't pull myself together and remain strong no one is going to encourage me* (Noni)

It is not only families and friends who can offer support. Formal support groups have been recognized for the important contribution that they make to positive psychological adjustment of those who are HIV-positive. One way in which support groups are useful is that they provide factual information (Friedland et al., 1996). Indeed, research shows that membership of such a support group mitigates against mental disorder regardless of how often the person actually uses the group (Freeman et al., 2007). This suggests that just knowing that you can access the support when it is needed can be beneficial. Again, the benefits are perhaps because membership of a support group refutes the people's self-appraisals that they are alone and different to everybody else.

An important aspect of the support that is provided by these support groups is to do with the knowledge they provide. Nandi decided to join a support group as she felt she needed to know more about the virus.

> *Coming to the support group here at the centre helped by providing me with the correct information because I learned in the group that being HIV positive does not necessarily mean that I am going to die soon and so on and so on* (Nandi).

Lihle on the other hand decided to obtain professional psychotherapy as she was struggling to accept her diagnosis.

> *Simple answer.....counseling. My mom is a big fan she went to Fort England after my father died for counseling so it helped her, so she kind of 'forcefully' recommended that I go so I took her advice . I attended I think for 5 to 6 months, I think that really helped me a lot to get to this point and obviously my mom ke I am sure I have mentioned her a hundred times already* (Lihle).

Thus, it is clear that social support is significant in developing adaptive coping strategies (Hinton & Earnest, 2010) and it also help to combat psychosocial stress (Pergami et al., 1993).

### 4.4.4 Theme 4: Coping strategies

People diagnosed with HIV/AIDS may use either emotion focused or problem focused strategies (Myint & Mash, 2008). Recall form the literature review emotion-focused strategies were defined as behaviours that people use to minimise distress. While problem-focused strategies are based on managing the problem that is causing distress (Maskowitz & Wrubel, 2005). Emotion-focused strategies are often considered problematic as they may hinder the process of psychological adjustment, while problem-focused strategies have been associated with positive psychological adjustment (Friedland et al., 1996; Lindner, 2006; Myint & Mash, 2008). Emotion focused strategies appear to be more prominent amongst recently diagnosed individuals because people usually adopt these strategies when they are still overwhelmed by the diagnosis (Friedland et al., 1996; Mynt & Mash, 2008).

#### *4.4.4.1 Social withdrawal*

Social withdrawal or isolation is one type of emotion-focused strategies that people use as a way of coping with the diagnosis (Reeves et al., 1999). However, social withdrawal has been associated with depressive symptoms and could also limit access to the much needed support (Medley et al., 2009). Social withdrawal appears to have been one of the strategies used by the women who took part in this study.

Nandi reported that she wanted to be alone all the time, they did not want to be around people:

> *I used to be so worried and I would want to sit alone and cry and I did not want anyone around me so if I start thinking I would go my bedroom and sit there and cry* (Nandi).

Lihle also describes that she wanted to be alone because she felt that being HIV positive had changed her:

> *I did not feel like being around people. Where I am there must laughter I am joyful and loving person but for that few weeks I had changed and I guess I was not comfortable with who I had become, it was not me* (Lihle).

Noni also explains how she would avoid people at home after she was diagnosed with HIV.

> *I was just feeling….uhmm how can I put this? I was in pain; I was just crying all the time and I was avoiding people at home* (Noni).

People may isolate themselves for various reasons including feeling overwhelmed by the diagnosis, feeling ashamed for being infected, and a fear of stigma and discrimination (Hackl et al., 1997; Medley et al., 2009; Steven & Hildebrandt, 2006).

#### *4.4.4.2 Alcohol abuse*

Alcohol is another form of emotion-focused strategies that people may adopt following an HIV positive diagnosis. Some of these strategies are considered destructive (Hackl et al., 1997; Myint & Mash, 2008; Reeves et al., 1999, Olley 2009). The Literature suggests that alcohol abuse is common with those who are HIV-positive (Kelly et al., 2008). It may be an important factor that puts people at risk of HIV infection in the first place and puts them at further risk after being re-infected (Freeman et al., 2008; Kalichman et al., 2007). Noni reported that she was drinking before she was diagnosed which would have placed her at risk of infection. However, she admitted to her drinking escalating after she received the diagnosis.

> *No it was not a new thing I usually drink a lot. It has always been like that so I guess it just became worse in that week because I drank every day***.** *I don't know I was just drinking on a daily basis which is not something I usually do, maybe I had not accepted but I did not think of it that way* (Noni)

As discussed in chapter two, people living with HIV/AIDS may use alcohol or substances as way of escaping unpleasant mood states or as a way of avoiding traumatic thoughts memories which can also be linked to increased sexual risk (Young, 2011). Even though Noni has stopped drinking for a few months prior the interviews, it appears that she might have used alcohol to help her minimise the pain she felt as a result of being diagnosed.

> *Yes I have I stopped drinking I think……in November last year I stopped; and I have not touched alcohol since then* (Noni)

Literature around alcohol use suggests that South Africa is one of the heaviest nation drinkers in the world and has long been a way of life for many and has also been identified a major contributor on the spread of HIV/AIDS (Kalichman et al., 2007). Thus, is not surprising that alcohol puts people at risk of HIV and that alcohol is a common though risky way in which people cope with their HIV status.

#### *4.4.4.3 Heightened spirituality and religiosity*

Spirituality has been known as a coping strategy used by most people when they are faced with difficult challenges (Dagied & Duckert, 2008). Some people may turn to God as a way of maintaining hope. This strategy has been defined by different authors as both emotion-focused and problem-focused (Harris & Larsen, 2008; Lekganyane & du Plessis, 2011). Most of the women in this study sought support from their belief in God and from the fellowship of the church.

Lakhe felt that turning to God would ease the burden she felt after being diagnosed with HIV.

> *My sister I am a Christian, I go to church. I decided not to carry the burden on my own because I realised it would kill me so I just gave everything up to God because God is*

> *the creator he knows me, so I do not even stress about things if I see that there is something bothering me I will pray about it.....I always ask God to grant me more years so that I can raise my child....I just told myself that I will not be tormented by a border in my body, it is going to go back where it comes from* (Lakhe).

Psychologically, the benefit of this is that people can believe that they are protected and not subject to random acts of misfortune, and that their lives with HIV have meaning.

Lihle felt through her faith she can be able to face day to day challenges of being HIV positive and may prolong her life. Again, it is not just her belief in god that is important to her, but also the support that she receives from other members of her church.

> *I go to church as well and people there are very supportive, like they are always checking up on you and trusting in God just gives hope that I can overcome my challenges. I am not one of those that believe that God will heal me, but he can keep me in good health and that is all I want. No, like I have always believed in God and I know that my faith in him helps me to cope with difficult situations, but it has always been like that* (Lihle).

Nandi also became more committed in her church activities after learning about her status

> *I also went to church you know it is very easy to think of God when you are in trouble and in church I felt comfortable like people in church just accept you so I needed that acceptance at the time, but going to church was not a new thing for me I had always been a church goer I just became more committed to it after I came back from Joburg* (Nandi).

Some available literature suggests that in some cases the Faith–based-Organisations might have a source of stigma in past (Skinner & Mfecane, 2004). This is based on the religious teachings that portrayed HIV/AIDS as punishment from God and condemn people that are HIV positive (Skinner & Mfecane, 2004; Oppenheimer & Bayer, 2007). Therefore, in such a context, one might assume that going to church could be a way that one might use to counteract these perceptions and beliefs as being a church goer might be associated with purity. Also if such perceptions had been internalised or if the participants held similar views about HIV/AIDS, one might assume that going to church might also be used as a way of denying one's negative appraisals of their self. The problem is that when such is done, one might not be dealing with the actual appraisals, which may remain intact and when they are faced with a similar problems these negative appraisals maybe re-activated (Boulind, 2014).

#### 4.4.4.4 Change of lifestyle

For many people receiving a positive diagnosis can lead to either positive or negative changes. Most people after being diagnosed HIV positive will report at least report change in certain aspects of their lifestyles (Dagied & Duckert, 2008). Positive changes could include adopting a healthier lifestyle like eating healthy, exercise and limiting alcohol intake or stopping altogether (Dagied & Duckert, 2008). The women in this study also reported that they had to change certain things in their behaviour.

Nandi explains that she decided to limit her alcohol intake and also ensure condom use every time she has sex.

> *The only change I made was with alcohol, I used to drink a lot like maybe every weekend but now I don't drink as much I know that I cannot afford to drink like I used. For instance I will only drink a cider or two on Christmas day and New Year's Day that's it because I know my situation…. Like I said even if I am going to have sex I must use a condom, unlike before where I really did not bother myself much about such things* (Nandi).

Noni reported that she decided to quit alcohol altogether

> *Yes I have I stopped drinking I think……in November last year I stopped; and I have not touched alcohol since then* (Noni).

People may become more responsible after contracting HIV; this may be used to counteract the charge or appraisal that they are irresponsible, which is often levelled at those who are HIV-positive because HIV is usually considered avoidable (Boulind, 2014).

#### 4.4.4.5 Focusing on living (duty/obligation to others)

According to Green and Sobo (2000), when people have adjusted positively to the diagnosis of HIV/AIDS they may decide to focus on other important things in their lives, rather than focusing on the impact of the illness itself. For women that had children, this proved to be true because they had to do everything possible to ensure their survival for the sake of their children.

Lakhe and Nandi describe how thinking about their children motivated them to want to carry on living.

> *The problem is I have a child so if I focus too much on this thing* (HIV infection) *and end up dying who will look after my child and it is also my wish even if there is someone who can look after my child I would also like to see my child grow up* (Lakhe).

> *No, it is one of the reasons I decide to look for help because I still had my so son and I did not like having thoughts of ending my life. I still wanted to see him grow up* (Nandi).

Noni's hopes for giving her son a better future also encouraged her to change her lifestyle and focus on living a positive life.

> *I don't know because I guess the reason I am not dead by now or is because I want live for my son because I am hoping that maybe one day I will be able to live with him an give him a better life than I have had, not say that I am going to become rich or anything but better in the sense that I can give him love instead of the abuse that he gets* (Noni).

Although not clearly evident from the current study, there seems to be a healthy shift from emotion-focused to problem-focused coping. The literature also suggests that coping may change over time and HIV-positive individuals may employ problem-focused strategies (Mynt & Mash, 2008). It would also appear that the women made some positive changes in their lives as a way of maintain physical well-being. However it should be noted that coping strategies that individuals choose to employ a heavily influenced by their contextual situation, therefore, it would be impossible to judge which coping styles are more appropriate due to the psychosocial challenges each of the women face (Dagied & Duckert, 2008).

Given that the women in the study came from poor socioeconomic backgrounds, they are inevitably also confronted by many other difficulties in their lives and so coping for them was not limited to dealing with a life-threatening, chronic illness, but also a host of life challenges.

### 4.4.5 Theme 5: HIV as one of many insults

Living with HIV/AIDS is considered traumatic. However in the contexts of other traumatic events that people may have endured in their lifetime, HIV may possibly be just one of many challenges with which they must deal (Ciambrone, 2001). Black women in particular have been known to shoulder many challenges including poverty and being in abusive relationships and these are also factors that seem to aggravate HIV/AIDS (Lindner, 2006; Ackerman & de Klerk, 2002; Simbayi et al., 2005). Women in this study also came from similar contexts.

#### 4.4.5.1 Poverty

The burden of poverty disproportionately affects women in developing countries, and has a circular relationship with HIV, where poverty puts people at risk for HIV and HIV puts people at risk for poverty (Lau & Muula, 2004). The high infections rates of HIV amongst women have been directly associated with poverty (Jewkes, 2009). One reason for this is that women in poverty are often financially dependent on their romantic partners and engage in transactional sex, where in exchange for sex, men provide material support (Jewkes, 2009). In situations like this, however, women have little power to negotiate safe sex (Fox et al., 2002; Jewkes, 2009; Ackerman & de Klerk, 2002). Women in these situations are usually well aware of the high risk of HIV infection; however the need to provide for themselves and their children supersedes the need to reduce the risk of HIV infection (Ackerman & de Klerk, 2002, Medley et al., 2010).

For Noni in order to keep her shelter she has to conceal her status from her partner as she would have nowhere else to go if evicts her from the house.

> *He is going to break up with me and throw me out if his house. The thing is I was raised by my grandmother and then she died last year and then she left me with my paternal aunt so I am not happy there because sometimes my aunt's son will throw me and my son out of the house when he is drunk and he would be swearing at us saying things like "you are useless, no wonder your mother left you (Noni).*

Noni's desperate situation means that she has very little power to negotiate safe sex. She reports that even though they are not using condoms, she cannot raise the issue as it might evoke suspicion from her partner.

> *No because he never brought it up and I also did not ask him because I thought he would become suspicious (Noni).*

Noni further suggests that she has no choice but to conceal her status despite worries about infecting him or being re-infecting herself.

> *That is what I worry about all the time, but I don't know because….No I don't know, yes I think about it but what can I do? Because if I am the one who talks about using condoms then he will suspect that I am hiding something from him and start asking questions (Noni).*

For Sino sex with different men is the only way she can ensure that her basic needs are met, including shelter, food, clothes and toiletries. Her excerpt clearly indicates that she was well aware of the risks, but the need for shelter and other basic good and her fear of stigma were greater.

> *I came back from PE and I was very promiscuous because I could not stay with mother because like I told she would beat me up and all that she did, so I had to sleep with men to have a place to stay and toiletries and then this is …then my aunt took me in and she said she could not bear to see her sister's child living the kind of life I was living. Even though I knew my status I could not disclose to my boyfriends, yes I was scared that I might be infecting them the virus, but I was unable to come clean and tell them my story because I was scared that they would end the relationship and gossip about me. I was already the talk of the town because of my behaviour and I could not give them any more stories to talk about* (Sino).

Literature on HIV/AIDS and poverty suggests that poverty has a major role in influencing sexual decision-making (Shisana et al., 2009). The point here is that rational decision-making in these contexts does not necessarily equate to safe sex. Being in poverty threatens day to day survival as it deprives many black women of necessary goods such as food and housing (Noble et al., 2004).

#### 4.4.5.2 Abandonment by parents in early childhood

Some of the women in this study had been abandoned by their parents from a very young age, and their HIV diagnosis was simply another of life's negative experiences (Ciambrone, 2001). Noni only met her mother recently and the meeting was very brief. She described how she heard about her mother leaving her and the trauma she had to endure over the years due to the absence of her parents.

She believes that when she received the diagnosis she did not have the right to go through the pain she felt because no one cared enough to console her. Thus, feeling sad would be a luxury she could not afford, a waste of time:

> *You see I did not grow up with my mother, I heard she left me with her brother when I was 3 days old and her brother took me to my paternal grandmother. My father was in prison, he went to prison before I was born. I have also dealt with many difficult situations and that did not kill me so I will carry on because what can I do?* (Noni).

Sino on the other hand expressed how she was abandoned by her mother as a child and she further states that even when they reunited later in life she suffered a great deal of physical and emotional abuse.

> *My biological mother hated me; she told me that I was evil saying "this thing that has a dead father" and yet she abandoned me when I was young because I would not even have had a child if she was around. Even when I had a child I left the father of my child in PE and came back home, my mother would beat me up, throw away my baby's nappies outside, I still have old scars in my head from when she would beat me up because she would hit me with anything and I would bleed* (Sino).

The experience of being abandoned by the biological mother appears to have been more devastating than receiving a diagnosis of HIV. The participants seem to have gone through a great deal of trauma as a result of their parents' absence in their lives. Thus, the diagnosis of HIV may have been just another event in their lives.

#### *4.4.5.3 Gender-based violence*

Gender violence places women at risk of HIV infection because it creates an environment where women are disempowered, especially in terms of decisions about sex (Jewkes et al., 2003). Physical and emotional abuse diminishes women's autonomy, leaving many powerless and helpless. Gender-based violence is a consequence of and reinforces gender inequality and patriarchy. The upshot is that many women struggle to protect themselves because even if they are dissatisfied in the relationship, they are unable to speak up, due to fear of being beaten (Ackerman & de Klerk, 2002; Simbayi et al., 2005). In some cases men will assault women in order to make sure that they submit to their sexual demands (Jewkes, 2009).

Noni reports how her former boyfriend would beat her up even in public.

> *He did not want to break up with me like if in that past I tried breaking up with him he would beat me up and drag me on the street, so that is why I never broke up with him* (Noni).

Sino describes her experiences of being abused by her boyfriend and how he would demand sex.

> *I had just had a baby so I was being abused and my boyfriend would demand sex even when I did not want to, so I decided to come home (Sino).*

It has been reported that gender-based violence has become a norm because of its high prevalence in the South African community (Outwater et al., 2005). Noni's excerpt might serve as evidence of this because she was assaulted in the community to a point where she was forced to leave home and is currently hiding from her former partner.

> *I can't because even if I go home now his father will go and get me from home and he will beat me up* (Noni).

Gender-based violence appears to have been one of many other problems these women encountered and one might assume that it may have placed them at risk of being infected in the first place.

## 4.6 Conclusion

This chapter has discussed the findings of the study. The discussion draws on the participants' accounts and locates these within the relevant literature. The findings support the idea that stigma plays a role in how people view and experience their diagnoses of HIV. Stigma also appears to have major role on people's negative self-appraisals following a diagnosis of HIV. The meaning of the diagnosis was also largely shaped about the perception of others. Decisions about disclosure appear to be largely influenced by stigma. However, it seems participants opted for partial disclosure to protect themselves from stigma and discrimination, but still access the medication and support they need. Another significant finding was that for some women in the study, though the diagnosis was very stressful to navigate, living with HIV is sometimes simply regarded as just one of many life challenges that they must endure. Coping is shaped by different circumstances that these participants faced. Membership to a support group, church or attending on-going counselling seemed to have helped the women in the study to cope well.

# CHAPTER FIVE: CONCLUSION

The main aim of the study was to try and provide an account of the subjective experiences of women who have been recently diagnosed with HIV. The study therefore offers some insights on how these women make sense of an HIV-positive diagnosis, the impact of stigma and how other traumatic life events have translated in how they view themselves and subsequently cope with HIV. This study was conceptualised and conducted within a qualitative research paradigm using, Interpretative Phenomenological Analysis in order to be able to access the participants' subjective experiences. This method assisted the researcher in understanding how people assign meaning to their experiences based on their context. Because of its theoretical foundations, IPA provided the researcher with the theoretical lens and tools of analysis in order to achieve the aims of the study.

Importantly, the study offered a few marginalized women an opportunity to share their experiences. Studies of similar nature are usually conducted in the Western Cape and participation becomes limited to those that can speak English and Afrikaans, which suggest that women who are monolingual cannot participate.

A number of commonalities emerged in the findings, even though there were also few variations on individual experiences. Important to note is that the women did not perceive themselves to be at risk of infection, even though they were all sexually active and not using protection. Therefore, women were surprised by receiving an HIV-positive result. All women chose to disclose their status through partial disclosure in order to protect themselves from stigma and discrimination. Disclosure is a key element of accessing social support. After disclosing to close family members and friends, some of the women were stigmatised and discriminated against, by some of the 'trusted' people they had hoped would support them. Being a member of a support group, having home visits from care workers as well as profession therapy appear to have made the women feel some sense of relief and cope better with their diagnosis. Women in the study developed different coping strategies both emotion-focused and problem-focused. However, some coping strategies could be called compensatory as they appeared to be aimed at compensating for past behaviour and further re-enforcing negative appraisal about self. Lastly, HIV-positive diagnosis was not necessarily viewed as the most threatening and disruptive life event, due to an array of other traumatic life challenges that these women have had to deal with in their lifetime.

## 5.1 Implications of the study

As discussed in this research, individuals suffering from HIV may be faced with stigma and other mental health problems. Stigma seems to continue being potential obstacle in to accessing support and other interventions that may maintain mental health (Collins & Freeman, 2009). Therefore, interventions to reduce stigma continue to be needed.

It has also been identified through previous research that mental health problems are a cause and a consequence of HIV (Brandt, 2009; Collins & Freeman, 2009; Kelly et al., 2008). Psychopathology was not as apparent in the current study even though there were events that could account for such difficulties prior and following an HIV diagnosis.

One of the factors that seem to have had a major impact on the women was poverty. It is apparent from this study use of emotion-focused and compensatory strategies may be prominent in the context of stigma and poverty. A problem with what appear to be compensatory coping strategies is that these may leave problematic appraisals intact. Thus, would be useful to integrate mental health care programs in the public health sector in order to address these problems.

The findings also suggest that poverty continues to be a challenge for women who come from poor socioeconomic backgrounds. The initiative of disability grants for people suffering from

HIV/AIDS-related illnesses may be a good start; however there is a need for more initiatives that will help empower women living in poverty-stricken conditions. Poverty alleviation efforts should reduce the risk of HIV infection and allow those already infected to better cope with their situations. Further research with larger and more diverse samples should be conducted to further explore the themes reported here and to develop interventions that empower women.

Lastly, the study was conducted through a Non-Governmental Organisation working with PLHA and the importance of the work that these sorts of organisations do should be recognised, especially in times of economic hardship and funding cuts that put such organisations under severe operating strain.

## 5.2 Limitations of the Study

Some people might view a small sample as a limitation, but IPA actually recommends small homogenous samples so as to be able to explore in-depth, convergence and divergence of experiences. One limitation however is that the interviews were conducted in isiXhosa and translated by the interviewer into English for analysis. The benefit of this is that it allowed the participation of people who are unable to speak English or Afrikaans. A limitation is that some of the meaning or richness of the data might have been lost in the translation. IPA involves a double hermeneutic whereby the researcher tries to make sense of the participants who try to make sense of the experiences, and thus the language translation adds a whole new layer of interpretation.

Nevertheless, despite the limitations described above, the findings are often consistent with other findings reported in the literature and supported by detailed excerpts that suggest that they are valid and meaningful.

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# APPENDICES

## Appendix A

### Interview Schedule

1. Could you please tell me about yourself
2. When did you discover that you were HIV positive?
3. What made you decide to test?
4. How did you feel when you were told that you are HIV positive?
5. What went through mind after hearing the news?
6. What was your initial reaction? Could you describe specific thoughts, feelings or behaviours?
7. What does it mean to you to be living with HIV?
8. How did you see yourself before the diagnosis?
9. How do you perceive yourself now?
10. What were other people's perceptions of you before you were diagnosed HIV positive?
11. What are other people's perceptions to you now that you are HIV positive?
12. Have you disclosed your status to anyone? If yes, what was their response to the news? If no, can you explain to me what your reasons for not disclosing are?
13. Have you experienced any form of stigma since you disclosed your status to people?
14. How has life changed as a result of the diagnosis? Or how has HIV impacted on your life?
15. Are there certain habits that you have adopted since you have become positive?
16. How do you cope or what helps you to cope (coping strategies)

## Appendix B

RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

### AGREEMENT

### BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT

I (participant's name) ____________________________ agree to participate in Khuselwa Juries' research project on my experiences of being a recently diagnosed woman with HIV, around stigma, HIV and Mental health.

I understand that:

1) The researcher is a Master's student conducting the research as a requirement for her degree at Rhodes University.

2) The researcher is interested in my experiences of living with HIV and my thoughts and feelings about my diagnosis.

3) I agree to participate in the individual interviews.

4) I am aware that participation in this study is voluntary and I can thus choose to withdraw at any time.

5) I will be asked to discuss matters that will be of a serious and sometimes personal nature. I recognise that I have the freedom to opt out of discussing anything that makes me uncomfortable.

6) If I experience any distress whatsoever, I am aware that the Jabeez Centre counsellors/care workers are available should I feel the need to discuss anything.

7) My identity will not be disclosed in the research findings and I am aware that my anonymity and right to confidentiality will not be violated.

8) I am aware that the interview will be audio-recorded and that the recordings will be transcribed for interpretation, after which the recording will be erased.

Participant signature: ______________________ Researcher's Signature____________________
Date: _______________

## Appendix C

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DEPARTMENT OF PSYCHOLOGY
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Mr. Goodwill Furtherstone
Director of the Jabez HIV/AIDS Centre
Grahamstown
March 2014

Dear Mr Furtherstone

**Permission to approach Jabez Centre to recruit research participants**

I am currently doing masters in Clinical psychology at Rhodes University. I am conducting a research project on HIV and women as part of the requirements of this course. I have attached a copy of my research proposal for your consideration. The proposal has received approval of the Rhodes University Psychology Department's Research Proposal and Ethics Review Committee. The research project is supervised by Professor Charles Young from the Psychology Department.

The aim of the research is to explore appraisals made by women recently diagnosed with HIV. As the Jabez centre is one of the major HIV organisations in Grahamstown that works directly with HIV positive people, I would like to request for your assistance in locating participant for my research project. I would be glad to meet with you to discuss my research plans in more detail.

Yours Sincerely
Mrs Khuselwa Jurie
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Cell: 0837302278