THE EXPERIENCES OF RECENTLY DIAGNOSED HIV-POSITIVE INDIVIDUALS, AS SHARED ON AN ONLINE FORUM

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Abstract

An HIV-positive diagnosis can be an overwhelming and traumatic experience. This study explores the experiences of receiving an HIV-positive diagnosis. Employing an Interpretative Phenomenological Analysis (IPA), a sample of the initial posts from threads on an online forum, was collected and explored, in order to determine the dominant themes from the experiences expressed in the posts, as well as the support sought from the forum. The online forum was accessed as an unobtrusive observer, and posts from January to December 2015 were explored. The online forum provides a platform for disclosure following an HIV-positive diagnosis, when anxiety and fear of stigma can impact on an individual's ability to disclose to their social support network of family and friends. The experiences expressed on the online forum reflect the emotional, mental and physical impact of an HIV-positive diagnosis on an individual. The findings in this study reflected themes of shock, guilt and hopelessness, and concerns and fears regarding disclosure and stigma associated with HIV, as well as the importance of social support for the coping mechanisms of individuals after receiving an HIV-positive diagnosis. This research demonstrates the importance of Internet accessibility for information and support for chronic illnesses, such as HIV, and the role of the online forum platform for providing a safe environment for individuals recently diagnosed HIV-positive.

Declaration

I declare that this research report is my own, unaided work. It is being submitted for the degree of Master of Arts (Counselling Psychology) at Rhodes University, Grahamstown. It has not been submitted before for any other degree or examination at this or any other university.

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Charlotte Anne Wylde

______ day of ________________, 2017.

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This thesis is dedicated to my late brother, Robert Kellgren Burns Wylde, who passed away during the writing of this research.

"His life was gentle, and the elements so mixed in him, that nature might stand up and say to all the world, This was a man!"

William Shakespeare

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Chapter 1: Introduction

"Receiving a diagnosis of being HIV-positive is an encounter with an agent of death but may also be the start of a journey into a life lived more meaningfully and fully…such a person does have the possibility of changing his/her inner attitude from despair to hope, from facing the inevitably of death to the potential for engaging in a life lived more fully and significantly" (Gosling, 2008, p. 264).

1.1 Introduction

A diagnosis with a serious illness is confronting, and of no normal place in one's life, as we all live in hope that the illness will never happen to us (Bartlett & Finkbeiner, 2006). An HIV-positive diagnosis is highly stressful for an individual, as it is often experienced as a life-changing and traumatic event (Cain et al., 2013). HIV is an infection of the immune system, which destroys or impairs the functioning of the system's cells, and results in a deteriorated immune system, which becomes deficient without antiretroviral treatment, and unable to fight other infections and disease (World Health Organisation [WHO], 2016). According to the World Health Organisation, in 2015 the number of people living with HIV was approximately 36.7 million and there were 2.1 million new HIV-positive diagnoses globally within 2015 (WHO, 2016). As a dominant chronic illness on a global scale, the availability of information on HIV, and support for those living with HIV, are key concerns for health professionals (Mo & Coulson, 2008). In 2015, the United Nations met its target of providing access to antiretroviral treatment for 15 million people across the globe (The Guardian, 2015). This is a significant achievement for helping people living with HIV, with an expected 19-year life expectancy increase since 2001

(The Guardian, 2015). Therefore, with the increased accessibility and availability of antiretroviral drugs, a diagnosis with HIV may no longer be seen as a sentence to death, and in light of this, the experience of receiving an HIV-positive diagnosis may therefore keep evolving in the future.

There are a number of reactions experienced by individuals when receiving an HIV-positive diagnosis. Some of the most commonly reported reactions are feelings of disbelief and complete shock, as well as confusion, blame, fear, anxiety, sadness, depression, devastation and fury (Bartlett & Finkbeiner, 2006; Cain et al., 2013; Stevens & Hildebrandt, 2006). Some newly diagnosed HIV-positive individuals experience a longing for their old self, and feel anger for this loss (Lingen-Stallard, Furber, & Lavender, 2016). People make use of different strategies for dealing with the feelings surrounding an HIV-positive diagnosis (Bartlett & Finkbeiner, 2006). Through sharing diagnoses, and talking with other individuals infected with HIV, newly diagnosed individuals may experience a sense of warmth and hope, as they feel less isolated and gather strength from the stories of others and their individual coping strategies (Bartlett & Finkbeiner, 2006).

The Internet has grown enormously since it began and the use of social media, online chat rooms and forums has expanded the way in which people share stories and communicate with each other. According to research, the Internet is growing in its use as a source of health-related information, and in a study exploring Internet use, just over 50% of participants accessed chat websites when searching for online health information (Alghamdi & Moussa, 2012). The use of the Internet by HIV-positive individuals for online support and information, and to improve health and well being, has been suggested as a widely used strategy for coping with the illness (Kalichman et al., 2005). Specifically, the use of the Internet for people recently diagnosed as HIV-positive, may be an important source of resources (Courtenay-Quirk et al., 2010; Horvath et al., 2010; Walsh, Horvath, Fisher, & Courtenay-Quirk, 2012).

1.2 Overview of the research

This exploratory study examined the experiences of recently diagnosed HIV-positive individuals, as shared on an online forum. The research follows the qualitative approach of Interpretative Phenomenological Analysis (IPA), with a focus on exploring, trying to understand, and analysing, how individuals make sense of their experiences (Smith & Osborn, 2003). IPA assumes that the researcher is aiming to learn about the world of an individual and the experience being studied, and therefore, an attempt to understand the complexities surrounding the meaning of an experience for an individual, is paramount (Smith & Osborn, 2003).

The data collected in this study consists of the initial posts from threads on an online forum, where self-identified HIV-positive individuals describe their experiences of receiving the diagnosis; express their thoughts, concerns and feelings, and request for advice and support. The 140 initial posts across various threads, from January to December 2015, were collected through accessing the online forum as a guest and an unobtrusive observer. The data collected from the online forum was copied and pasted into a word document, and analysed according to an interpretative phenomenological approach. The analysis process involved immersing oneself as the researcher in the text, identifying and connecting themes and, finally, producing a list of superordinate themes for discussion. The data collection procedure typical for IPA is semi-structured interviews, however, for this research, the data was collected from the posts on an online forum. This type of procedure for data collection, with the data analysed within an IPA framework, has been done in other studies exploring experiences of illnesses. This design was chosen as the data is unmediated, and therefore the experiences explored are likely to be without any outsider influence, and a number of different lived experiences for individuals in the own environment could be explored.

The findings from the analysis demonstrate the impact that the fear of stigma has on the experience of receiving an HIV-positive diagnosis, as is discussed in the literature. The findings from this study also suggest that feelings of shock, confusion, guilt, hopelessness and a sense of self-blame are experienced following an HIV-positive diagnosis, and impact on decisions regarding disclosure. Finally, the influence of social support, as well as the benefits experienced from access to the online forum, are also discussed in the findings of this study.

1.3 Chapter content

The second chapter in this study is a discussion and review of relevant literature focusing on the experience of receiving an HIV-positive diagnosis; the complexities surrounding disclosure, experiences of shame and different types of stigma; the role of social support, specifically online social support, for HIV-positive individuals, and the relationship between access to the Internet and HIV within South Africa. The third chapter provides details of the research design, theoretical framework, sample, data collection and analysis processes, reliability and validity, and the ethical issues considered. The fourth chapter is an integration of the findings and discussion, as it describes and discusses the results of the analysis and the five key themes identified in the findings. Finally, the fifth chapter is the conclusion for the research. This final chapter provides a summary of the main findings, including a reflection on the research, the limitations of the study, and suggestions for further research.

1.4 Conclusion

This chapter provided a brief introduction to the research and the chapters to follow, including the literature reviewed, the methodology undertaken, and the main elements of the findings from the study. Within an IPA framework, this study focuses on the experiences of recently diagnosed HIV-positive individuals, as shared on an online forum, and the following chapters will explore and discuss these experiences through the literature, analysis and findings.

Chapter 2: Literature Review

"I carry in me now, a memory like blood, the shock of my own diagnosis, the long years of muteness and secrecy, the fear of fleshly failure, the allies I harboured and nurtured within of the stigmas and hatreds outside. I know that I have AIDS. It is not just that I refuse to forget. It's that I cannot. Remembering is in me, like blood." (Cameron, 2005, p. 214).

2.1 Human Immunodeficiency Virus (HIV)

HIV was first discovered in the 1980s and has since grown to be defined in terms of both a medical issue, with interventions to understand and suppress the virus; as well as a behavioural issue, with worldwide education campaigns aimed at informing individuals of how to prevent themselves from becoming infected (Holden, 2004). Besides the visible physical consequences of AIDS (Acquired Immunodeficiency Syndrome) or untreated HIV infection, people diagnosed with the illness have to cope with issues relating to their social, emotional and psychological lives (Reeves, 2000). There are great emotional difficulties and turbulence that are experienced by people infected, and affected, by HIV.

Highly Active Antiretroviral Therapy (HAART) is the combination of drugs necessary to suppress the progression of HIV infection and prevent AIDS (Bartlett & Finkbeiner, 2006). HAART treatment inhibits the lifecycle of HIV, and requires complete adherence to the treatment schedule in order to impact on the course of the illness, due to the risk of the virus becoming drug resistant should doses be missed (Bartlett & Finkbeiner, 2006; Chizanga, 2010). While HAART has provided a treatment regime with greatly improved future prospects for individuals living with HIV, there remains a high degree of uncertainty surrounding an HIV-positive identity (Brashers et al., 1999; Seeley et al., 2012). The uncertainty revolves around the monitoring of one's CD4 count and health status, fear of whether the therapy will work and whether there is a great enough supply of medication for lifetime therapy, as well as the reality of the lack of a cure, and the fact that the virus lives on in one's body forever (Seeley et al., 2012).

2.2 The experience of an HIV-positive diagnosis

A diagnosis of, and subsequent learning to live with, a chronic illness has significant implications for an individual's identity, self-esteem and sense of being (Charmaz, 1997, as cited in Di Risio, Ballantyne, Read, & Bendayan, 2011). A diagnosis with a chronic illness requires an adjusted sense of self, learning to cope with uncertainties about the future, and the management of expectations for changes to pre-existing relationships, goals, desires and identities (Charmaz, 1997, as cited in Di Risio et al., 2011).

The experience of receiving an HIV-positive diagnosis can create mixed emotions in the receiver and the way in which a diagnosis is provided can impact on the experience of the initial diagnosis. Hult, Maurer, and Moskowitz (2009) explored individuals' experiences of receiving an HIV-positive diagnosis, through face-to-face interviews, and the way in which the news was conveyed, as well as the interaction with the health service provider, had an impact on the experience of receiving the diagnosis for the participants. The way in which a diagnosis is delivered can be a mixture of a negative and positive experience, depending on the way in which the counsellor or nurse comforts, and puts the individual at ease, through reassuring and calm discussion (Hult et al., 2009). Initial responses to receiving an HIV-positive diagnosis range from physical reactions such as dizziness, sweating or crying, to emotional reactions of shock, surprise, and sadness; as well as feeling the need to run away and feeling that the reality is surreal (Hult et al., 2009). The way in which a diagnosis is conveyed can have a positive influence on the experience, if provided by a competent, empathic and sensitive counsellor or nurse, attuned to the emotions experienced on receiving the diagnosis (Hult et al., 2009). Therefore, the way in which a diagnosis is provided may have an effect on the actions taken by individuals following a diagnosis, and the subsequent feelings experienced.

In a study conducted into the exploration of the stressors experienced by youth on receiving an HIV-positive diagnosis, a number of themes emerged (Martinez, Lemos, & Hosek, 2012). The stressors identified included the psychosocial responses of anger and depression, and the emotions involved with accepting the diagnosis, as well as fears around stigma and decisions of disclosure (Martinez et al., 2012). Other stressors identified were those of concern for the bodily changes that would soon take hold, the treatment regime and side effects thereof, as well as feelings of needing to adjust life goals and future plans, including concerns around reproducing and creating a family (Martinez et al., 2012).

From the initial emotions of shock, disbelief and anger after receiving an HIV-positive diagnosis, an individual's personal resilience may help to move them to an acceptance of their new self and a reduction in the power of HIV over their lives (Lingen-Stallard et al., 2016). People cope with the trauma of receiving an HIV-positive diagnosis in different ways, however, having a reason to live, and the support systems in place to assist with this optimism, may be one of the strongest mindsets for survival. Coping can be defined as the "cognitive or behavioural response to something appraised as stressful" (Moskowitz, Hult, & Bussolari, 2009, p. 121). The ways in which HIV-positive individuals are able to adapt to living with the virus, and cope with daily stress and management, impacts on overall well-being and mental, emotional and physical health (Penedo et al., 2003). Individuals who are unable to overcome the adversity of an HIV-positive diagnosis, confront and adjust to the new reality, and disclose their status to mitigate the perceived, and perpetuated, isolation, may have more hope of mitigating the development of mental health concerns of depression, substance abuse and lack of hope for the future, which are high amongst HIV-positive populations (Kelly, Freeman, Nkomo, & Ntlabati, 2008).

Research into the process and mechanisms for coping suggest that two coping strategies are dominant: "approach-oriented and avoidant-oriented strategies" (Penedo et al., 2003, p. 203). The two different processes can be characterised by the strategies of actively looking for and engaging with support, proactively solving problems, and accepting the virus, or disengaging and denying, respectively (Penedo et al., 2003). Research suggests that taking direct action shortly after receiving an HIV-positive diagnosis in respect of searching for a health care provider, making decisions regarding treatment and finances, and managing adherence to medication, have a positive impact on the mood and health of newly diagnosed HIV-positive individuals (Moskowitz et al., 2009). The active and proactive cognitive strategies involving reshaping one's situation into a positive light, reframing the diagnosis, and accepting the change in one's life, can improve the quality of the life of an individual living with HIV and help to decrease negative mood (Moskowitz et al., 2009; Weaver et al., 2004). Adaptive coping mechanisms can assist with providing better health and quality of life for HIV-positive individuals, instead of coping strategies which are oriented towards avoidance and denial, and tend to cause greater emotional and psychological concerns, and often lead to depression (Gibson et al., 2011; Penedo et al., 2003; Schmitz & Crystal, 2000; Weaver et al., 2004).

In South Africa, and other developing countries, greater effort needs to be given to including mental health care, information and support in the country's HIV and AIDS projects, in order to address the high levels of mental illness associated with HIV (Freeman, Nkomo, Kafaar, & Kelly, 2008). Research has demonstrated the high prevalence of mental illness among HIV-positive populations may be due to risky behaviours associated with some mental illnesses leading individuals to contract the virus, or as a result of factors following the diagnosis, such as negative coping mechanisms and experiencing a lack of social support (Freeman et al., 2008; Kelly et al., 2008). Socio-economic status has been shown to impact on mental illness levels amongst HIV-positive individuals, where the combination of unemployment, poverty and an HIV-positive diagnosis, has a negative effect on mental health (Freeman et al., 2008). Research into mental illness amongst HIV-positive individuals conducted within South Africa, indicates that the shock experienced following an HIV-positive diagnosis often leads individuals to either become depressed or abuse substances in maladaptive attempts at coping (Freeman et al., 2008).

Disengagement strategies have been found to be the least effective in coping with an HIV-positive diagnosis (Moskowitz et al., 2009). Avoidant coping strategies such as denial may be helpful in the short term for managing with an HIV-positive diagnosis, however, in the longer term they may add to the distress of individuals as they adjust to symptoms, adhere to medication, experience side effects from antiretroviral treatment, and possible experiences of stigma (Weaver et al., 2004). The use of coping mechanisms involving alcohol, drugs, socially isolating oneself, as well as distancing oneself from the reality, or giving up trying, are some of the disengagement strategies that can have negative effects on the well-being of an HIV-positive individual (Moskowitz et al., 2009). Maladaptive coping mechanisms such as alcohol and drug use, and denial, often lead to psychological instability, depression and poor adherence to medication (Lyimo et al., 2014). Jha, Plummer and Bowers (2011) reported in their study into the coping mechanisms of people living with HIV in Nepal that drugs and alcohol are often used in the acute phase of a diagnosis, however, later on through counselling and correct use of medication, confidence for surviving with the virus assists in building positive thoughts on coping.

The literature on coping mechanisms for people diagnosed HIV-positive suggests that spirituality, by means of religion, meditation, faith or prayer can also have a positive impact on the psychological well-being of HIV-positive individuals (Maman, Cathcart, Burkhardt, Omba, & Behets, 2009). The stress related to living with HIV has also been found to be reduced by individuals interacting with other HIV-positive individuals, by sharing stories and feelings, individuals experience a sense of belonging, of affirmation, of shared values and ways of coping (Jha, Plummer, & Bowers, 2011).

Stressful circumstances, maladaptive coping strategies and feelings of mastery interact to impact on an HIV-positive individual's quality of living (Gibson et al., 2011). Research suggests that feeling some mastery over HIV can assist with moderating the stress experienced from maladaptive coping mechanisms; substance use, denial, avoidance, and, in turn, having a sense of mastery can assist in the use of healthy coping mechanisms (Gibson et al., 2011). Providing support for HIV-positive individuals through counselling, and building skills for making use of more adaptive and healthy coping strategies for managing the stressors associated with HIV, can help to improve psychological and physical well-being (Gibson et al., 2011). Coping styles, types and levels of social support, and attachment styles are associated with the states of mind of HIV-positive individuals (Turner-Cobb et al., 2002). Bowlby (1973, as cited in Turner-Cobb et al., 2002) identified three attachment styles: secure, avoidant and anxious-ambivalent, which arise in childhood from the relationship with a primary caregiver, and influence how distressing events and stressful life transitions are dealt with later in life. Therefore, attachment styles may be useful predictors for the way in which people adjust to living with HIV and AIDS (Turner-Cobb et al., 2002). Secure attachments and healthy interpersonal functioning are related to greater adjustment styles and more positive states of mind (Turner-Cobb et al., 2002).

There exists a connection between social support and the choice of coping strategies by individuals in that the types of social support available to an individual can impact on the coping strategies engaged in, and thereby affect the psychological health of an individual managing an HIV-positive diagnosis (Schmitz & Crystal, 2000). Therefore, higher levels of social support, encouragement, and availability of information and care, may have a positive impact on the way in which an HIV-positive diagnosis is appraised and how the individual chooses to cope with the diagnosis.

2.3 Disclosure, stigma and shame

Besides the ethical decision-making process of disclosure for HIV-positive individuals to inform those to whom they may have transmitted the virus, it can be very difficult deciding whom else to tell (Bartlett & Finkbeiner, 2006). The decisions surrounding disclosure, full or partial, are influenced by each individual's experiences and ways of coping with a diagnosis (Levy et al., 1999). On receiving an HIV-positive diagnosis, a process of decision-making regarding disclosure begins, whereby an individual processes the trauma of the diagnosis, decides to whom it would be appropriate to disclose, thinks through the negative and positive consequences of disclosure, and decides on the right time and place to disclose (Kimberly & Serovich, 1996).

People receiving an HIV-positive diagnosis may prefer to keep it a secret rather than disclose it to others and risk discrimination and rejection, at a time when support may be most needed in order to deal with health issues and decisions (Brashers, Neidig, & Goldsmith, 2004; Smith, Rossetto, & Peterson, 2008). An initial defensive coping response to receiving an HIV-positive diagnosis can be denial of the illness itself, due to the perceptions of stigmatised responses that may follow disclosure (Kerr, Miller, Galos, Love, & Poole, 2013; Nam et al., 2008). Stigma involves a process of particular groups of people becoming seen as socially unacceptable and unwanted due to a certain characteristic, or way in which they behave being seen as having less value (Goffman, 1963, as cited in Turan et al., 2017). Stigma can be understood in terms of the negative beliefs about others, the way in which people respond to stigma and internalise the negative judgements, and effects that stigma has on others, which is often in the form of discrimination (Deacon & Stephney, 2007). Deacon and Stephney (2007) emphasise the different layers to stigma and the importance of separating stigma from discrimination. Negative beliefs alone can have a significant impact on the identity and feelings of self-worth of the stigmatised, without them having experienced discriminatory actions (Deacon & Stephney, 2007).

Stigma is experienced by HIV-positive individuals due to certain beliefs and ways of thinking within society, where HIV is seen to be fatal, easily transmitted, the responsibility of the individual, and the physical appearance that may be visible with AIDS (Brown, Macintyre, & Trujillo, 2003). In the 1980s, the uninformed attitudes and stigma surrounding the virus meant that individuals reported strained and changed relationships with friends, family members, and colleagues, after disclosing their diagnoses (Bartlett & Finkbeiner, 2006). Although attitudes have now changed, and people have become more informed, there is still stigma surrounding the illness, and therefore, deciding to disclose one’s status is a complex psychological battle between fear of the disease and fear of reactions to disclosure (Makin et al., 2008). Stigma plays an important role in the experience of receiving an HIV-positive diagnosis. The presence and perceptions of stigma can negatively impact on the experience of a diagnosis and therefore increase the level of trauma felt from receiving the news of one’s HIV status (Zeligman, Hagedorn, & Barden, 2017). Stigma has an impact on disclosure of one’s HIV-status, as the fear of discrimination through disclosing can cause individuals to disclose their status less often (Zeligman et al., 2017). Fears regarding disclosure, and a negative view of oneself due to internalised stigma, can have a significant impact on the way in, and degree by, which an HIV-positive diagnosis is experienced by an individual as traumatic (Zeligman et al., 2017).

Stigma comes in different forms and, with regards to HIV and AIDS, involves two dominant types; secondary stigma for things associated with HIV, blame on others, fear of contracting the virus, association with death; and internalised stigma of feelings of low self-esteem and self-worth (Clay, Bond, & Nyblade, 2003, as cited in Deacon & Stephney, 2007). Stigma directed towards HIV-positive individuals can influence feelings of shame, create a tendency to withdraw from others, and the use of the coping mechanisms of denial and disengagement, avoiding one's reality, and the internalisation of symptoms (Bennett, Hersh, Herres, & Foster, 2016). The experience of stigma related to HIV can have the effect of increasing the feelings of shame within an individual which affect one's desire to be in social situations, and this, in turn, can impact on greater levels of depression (Bennett et al., 2016). In a study conducted on a sample of men and women living with HIV in Cape Town, South Africa, 30% of the participants indicated experiencing depression and these feelings were found to be associated with internalised stigma (Simbayi et al., 2007).

The "Health Stigma Framework" adds to the two dominant types described above and suggests that stigma related to HIV-positive individuals is experienced in three different ways: "enacted stigma", "anticipated stigma", or "internalized stigma" (Earnshaw & Chaudoir, 2009; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Turan et al., 2017, p. 284). Each of these pathways of stigma experienced by an individual, results in different responses and negative effects on health and wellbeing (Turan et al., 2017). The first type is that of stigma that has been enacted previously, and therefore when an individual has experienced discriminatory behaviour towards themselves, based on their being HIV-positive (Turan et al., 2017). The second type is when an individual anticipates being discriminated against due to their beliefs about the negative associations that others may make due to their HIV-positive status (Turan et al., 2017). The last experience is when stigma becomes internalised through an individual accepting discriminatory and obstructive thoughts, behaviours and actions, and internalising them to be applicable to their own selves (Turan et al., 2017). Each of the means through which stigma is experienced affects different aspects of an HIV-positive individual's physical, mental and emotional health. Therefore, research into the separate processes of stigma can help to inform interventions to assist with creating better quality of lives for HIV-positive individuals (Berger, Ferrans, & Lashley, 2001; Turan et al., 2017).

Within Southern Africa, stigma surrounding HIV and AIDS is still of great significance, and individuals living with HIV experience neglect and abuse (Patterson, 2005, as cited in dos Santos, Kruger, Mellors, Wolvaardt, & van der Ryst, 2014). In a study conducted by dos Santos et al. (2014) into the experiences of stigma for people living with HIV and AIDS within South Africa, results demonstrated that after disclosure of a positive HIV status, stigma and discrimination were widely experienced. In studies done in the USA and China, high percentages of participants expressed fear of HIV-positive people, as well as an unwillingness to befriend anyone living with HIV, and a view that those living with HIV should be separated from society (Herek, Capitanio, & Widaman, 2002; Lee et al., 2005). Therefore, the shame experienced by people diagnosed with HIV can be understood amongst these discriminatory and ignorant ills of society. While there may be health benefits and, if not always, social benefits to self-disclosure, there are, however, also negative consequences to keeping one's status a secret as it can cause further stress (Imber-Black, 1998; Pennebaker, Colder, & Sharp, 1990; Smith et al., 2008).

A further way in which to understand stigma in terms of how people react to individuals who have HIV, is instrumental or symbolic stigma (Herek, 2002). Instrumental stigma refers to the fear of the virus, apprehension around being in contact with the virus, and a desire to fully protect oneself (Herek, 2002). Symbolic stigma relates to the association of HIV with specific groups of people, and the discrimination and socially constructed hostility towards these groups (Herek, 2002). Here there often exists a double stigma with these individuals having already been marginalised before acquiring HIV and then receiving further discrimination. Even with advances in knowledge about HIV, a lack of sufficient education regarding the virus and how it is contracted, mistrust of the scientific research, and entrenched symbolic and emotional beliefs remain rife in society (Herek, 2002).

Ignorance surrounding HIV can lead to discrimination that is not associated with the blaming and shaming of stigma, because it is the lack of knowledge rather than informed negative beliefs that lead to the judgements on others (Deacon & Stephney, 2007). Brondani, Donnelly, and Postnikoff (2016) explored the way in which stigma is experienced by individuals living with HIV, and their findings suggest that even with greater degrees of resilience, self-stigma is often still experienced by HIV-positive individuals, as a result of a perception of stigma or the act of stigmatisation from health providers and others within their community. There is a continued need within society to facilitate educational discussions about HIV, the ways in which the virus is transmitted, and outlining treatment options in order to decrease the effect that stigma has on the health and quality of life of HIV-positive individuals (Brondani et al., 2016).

Stigma surrounding HIV disclosure may contribute to feelings of shame and self-blame for people living with HIV (Radcliffe et al., 2010). The shame experienced by individuals diagnosed, or living with, HIV or AIDS is undeniably linked to its enmeshment with sex, as a sexually transmitted infection (Cameron, 2005). The privacy and intimacy of a sexual act is exposed to the world, in the diagnosis of HIV, and with this comes feelings of being marked for life; and therefore, shamed (Cameron, 2005). The role of personal responsibility and blame for contracting an illness is confronted within the daily lives of individuals living with HIV and AIDS (Rier, 2007). Personal choices to engage in certain behaviours can result in one contracting HIV, however, social and psychological factors influence these decisions, and circumstances are often not within one's control (Rier, 2007). Therefore, the internalised shame of an HIV-positive diagnosis could be enormously damaging for individuals struggling to reach their own acceptance.

In a study into the relationship between stigma, social support, and "posttraumatic growth", the findings suggest that there is a significant connection between low experiences of stigma and high levels of social support, with the positive changes experienced by some individuals following the traumatic event of receiving an HIV-positive diagnosis (Zeligman, Barden, & Hagedorn, 2016, p. 141). This growth may be experienced by individuals following an HIV-positive diagnosis, in the sense of acquiring a new perspective and perception of one's life, and the way in which one functions in relation to the world (Zeligman et al., 2016). Social support can have a significantly positive effect on the quality of life of an HIV-positive individual, and, therefore, assist in strengthening the individual's ability to find growth from their new status (Zeligman et al., 2016). Of interest is the powerful impact of stigma, and most specifically, if one’s perception of stigma becomes internalised, the presence of social support may not be sufficient to combat the consequences of low self-esteem, stress and depression (Zeligman et al., 2016).

2.4 Social support and HIV

Social support has an important role to play in life. Often the level of social support received during significant life transitions, impacts on the mood of an individual going through a stressful life change (Turner-Cobb et al., 2002). Depression is often experienced following the stressor of an HIV-positive diagnosis, with feelings of hopelessness and a need to isolate oneself (Cain et al., 2013). It has been found that stronger relationships correlate with a more euthymic mood and therefore may influence experiences of depression (Turner-Cobb et al., 2002). Individuals living with HIV and AIDS benefit greatly, and cope better, from higher levels of social support (Coursaris & Liu, 2009). The process of moving from shock and denial to acceptance of one’s status, enables an individual to begin to feel able to, disclose, access support, and engage in health care and treatment options (Horter et al., 2017). The presence, and use, of strong support networks for HIV-positive individuals assists to slow the progression of the disease and improve general health (Siegel & Schrimshaw, 2000). However, although individuals may have supportive relationships with friends, family, and community organisations, concerns around stigma, discrimination and shame may impact on an individual accessing this support following an HIV-positive diagnosis (Reeves, 2000).

Unfortunately, a frequent consequence of an HIV-positive diagnosis is a decrease in the amount of social support provided to the individual, and a change in the number of personal relationships and the levels of support from these (Turner-Cobb et al., 2002). Smith and Rapkin (1995, as cited in Coursaris & Liu, 2009) reported that the need for social support by individuals living with HIV/AIDS was unmet in 40% of the sample of 224 participants. Individuals newly diagnosed HIV-positive, and those living with HIV experience various uncertainties in their making sense of the virus and amongst their interactions in society (Brashers, Basinger, Rintamaki, Caughlin, & Para, 2017). In a study conducted to assess the effectiveness of an intervention into the management of uncertainty amongst newly diagnosed HIV-positive individuals, the findings suggest that support from trained peers may assist in developing individuals' skills for communicating in order to better manage their uncertainty (Brashers et al., 2017). The intervention, through a series of sessions with trained peers, focused on gaining knowledge about HIV and treatment options, learning how to access information from other sources, including credible online resources, and developing skills for communicating with family, friends, and people within the medical field (Brashers et al., 2017). The findings from this study suggest that - through increasing an HIV-positive individual's confidence for making use of available social support, as well as accessing information about HIV and improving their own knowledge base - uncertainties can be managed (Brashers et al., 2017).

Traditional social support may not always be seen as the best option for individuals having received an HIV-positive diagnosis. Even though some individuals may have sufficient social support in their lives, online health forums are also accessed for emotional support from others living with the same condition, as it allows a sense of normalcy in an individual's perceived isolated and stigmatised existence in their world (Davison, Pennebaker, & Dickerson, 2000; Nolen-Hoeksema & Aldao, 2011). The increase in the availability and accessibility of online forums and support groups since 1995 has the potential for increasing the possibilities of the needs for support of HIV-positive individuals being met.

2.5 The role of online social support for HIV-positive individuals

With the use of the Internet having grown significantly over the last two decades, there has also been an increase in the number of individuals making use of online resources for issues of health (National Telecommunications and Information Administration, 2002, as cited in Mayben & Giordano, 2007). Internet-based research on health has focused on the accuracy of medical information accessed online, as well as the changing relationships between health service users and health practitioners, due to the accessibility of information online (Fox, Ward, & O'Rourke, 2005; Kitchens, Harle, & Li, 2014; Loader, Muncer, Burrows, Pleace, & Nettleton, 2002; Zermatten, Khazaal, Coquard, Chatton, & Bondolfi, 2010). Another focus of internet-based research has been on the interactions between individuals dealing with a variety of health issues, in online communities (Coursaris & Liu, 2009; Kirk & Milnes, 2015; Sandaunet, 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). This study is aligned to internet-based research focusing on specific conditions discussed in online communities, and this research is specifically focused on the experiences of individuals, as members of a newly diagnosed HIV-positive online community.

The use of online resources is likely to continue to increase, as people increasingly search for health advice and information, as well as access means of online support (National Telecommunications and Information Administration, 2002, as cited in Mayben & Giordano, 2007). Courtenay-Quirk et al. (2010) explored how recently diagnosed HIV-positive individuals use the Internet following a diagnosis and the results ranged from searching for basic reassurance about living with HIV, to treatment information including alternative treatment options. In a search to feel included in some community, and less isolated in the world, recently diagnosed HIV-positive individuals also seek social connections with other people living with HIV or with those who have also been recently diagnosed, and, therefore, online forums are accessed (Courtenay-Quirk et al., 2010). Computer-mediated groups, such as the many online forums available on the Internet, provide a space for individuals to communicate, to share support, and exchange stories and experiences based on a common grounding, such as an illness (Coursaris & Liu, 2009). Online forums have the advantage of being easy to access and providing a diversity of people, perspectives and experiences, with little time and distance barriers (Walther & Boyd, 2002; Wright, 2000). Therefore, through members accessing the sites from all over the world, the time differences allow for 24/7 availability, as well as information and resources from different countries (Walther & Boyd, 2002; Wright, 2000). Kirk and Milnes (2015) explored the use of online support for young people living with cystic fibrosis, and their parents, and the findings demonstrated that the participants formed friendships and bonds, which allowed them to openly express their feelings and share their stories. In online communities, information and support are shared through personal accounts, and acknowledgement and empathy for the difficulties with managing the shared illness (Kirk & Milnes, 2015).

The Internet is an important and resourceful source of information for HIV-positive individuals, and the benefit of being able to search, and socialise anonymously online, makes it very appealing (Benotsch, Kalichman, & Weinhardt, 2004; Courtenay-Quirk, Wolitski, Hoff, & Parsons, 2003). Through online forums and other interactive sites online, a variety of information and support is sought. The support sought includes other HIV-positive people's perspectives and support, friendships, relationships, and advice on, and experiences of, medications. Information and support are also sought about how others live with the virus and speak about it with their family and friends, as well as how others disclose their status to new romantic partners (Courtenay-Quirk et al., 2010).

Support groups online provide areas for people living with HIV to express and discuss experiences of fear, anger, and social isolation that arise from the stigma surrounding HIV (Mo & Coulson, 2008). In a study examining the use of the Internet by people living with HIV, the results demonstrated that the use of HIV related online chat sites was connected with more successful coping methods and decreased HIV viral loads (Kalichman et al., 2005). The anonymous space of online forums could be highly appealing for individuals recently diagnosed HIV-positive, in order to disclose their status, to what could be expected to be a sympathetic and understanding audience, without fear of discrimination. Beyond this fear, the very act of disclosing one's status is a compulsion to release the stress and anxiety of holding the knowledge alone (Levy et al., 1999). This study is focused on exploring the experiences of recently diagnosed HIV-positive individuals through their sharing on an online forum. The sharing on an online forum involves a variety of self-disclosure. In online communities related to health issues, people disclose their condition, knowledge and experience of treatment, and their experienced emotions as a means of inviting empathy (Pfeil & Zaphiris, 2007). The self-disclosure in online communities, in the form of telling one's story, acts as a powerful coping mechanism (Fan, Lederman, Smith, & Chang, 2014). Therefore, online forums can provide a safe space for individuals to disclose their status, break the pain of silence, and elicit support, without evoking discrimination.

Participating in online support groups and making use of the virtual spaces for accessing information and support for people suffering from illnesses, can assist with empowerment, which helps to increase the well being of the sufferers (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). In order for people to be able to manage a chronic disease, empowerment is critical as it enhances individual control of prescribed medicines and treatment regimes (van Berkel, Lambooij, & Hegger, 2015). Through discussions in online support groups aimed at improving the self-esteem of members, and providing support and information, members may empower one another (Kirk & Milnes, 2015). Empowerment seems especially significant with regards to people living with HIV, for whom the treatment regime is a daily, lifetime commitment. In a study researching the impact of Internet use on the coping abilities of HIV-positive individuals, Reeves (2000) found the promotion of empowerment to be a primary outcome for the participants. Empowerment for coping with HIV may be expressed in the form of confidence from gaining knowledge from the Internet, and expressing this confidence in the interactions in HIV online forums; or having more control over one's management of the illness (Reeves, 2000). Therefore, through the sharing of experiences, information and support in online communities for people living with HIV, there may be a number of positive outcomes, including the enhancement of treatment adherence.

Further to empowerment, an increase in social support and the benefits felt from helping others, through the use of the Internet, impact on the coping abilities of HIV-positive individuals

(Reeves, 2000). The use of chat rooms or online forums for support has been found to be helpful for people living with HIV, because they offer a safe space to share experiences with others who understand and can provide empathy and advice; as well as the fact that the online world is constantly available (Reeves, 2000). The mere act of expressing emotions and frustrations in an online support group, where the recipients have an understanding of the experiences, can be healing in itself for individuals feeling depressed and hopeless (Kirk & Milnes, 2015). A specific emotion experienced by individuals recently diagnosed HIV-positive, is that of loneliness (Courtenay-Quirk et al., 2010). There is evidence of a need to connect emotionally with others online, as well as to use online interactions to identify where other groups of people living with HIV are based, for face-to-face interactions (Courtenay-Quirk et al., 2010). Through helping others in online support groups, people are able to learn from one another and feel a sense of belonging and purpose in the world of the online community (Reeves, 2000).

There are, however, also some difficulties that come with the anonymity, immediacy and accessibility of the online world. Within social media, people post stories, opinions and experiences with a perceived safety of the computer-mediated communication. Along with the emotional support, advice and information provided on HIV and AIDS online forums, they are also platforms for judgements and attacks to be made through the anonymous safety of the online world (Rier, 2007). A sociological approach of individuals living with HIV as being passive beings, unable to take responsibility for their actions and decisions, as well as make any judgement on others, denies moral agency (Rier, 2007). This approach presupposes that HIV-positive individuals have not acted in accordance with principles of right and wrong and are solely responsible for their illness.

The posts on online forums for HIV and AIDS function as platforms for issues of moral judgement, responsibility and blame, to be discussed and debated, with participants exercising their moral agency (Rier, 2007). Online HIV and AIDS communities may function as places of moral coercion and where judgements are made in terms of advice regarding disclosure and treatment (Rier, 2007). Collective empowerment in online communities places people in assumed roles of being responsible for their own, and other members' decisions, and, therefore, free to make moral judgements regarding other members' condition and health (Rier, 2007). Many online forums are, however, moderated, offering some protection from such judgements and attacks being made; however, at times the emotional damage may have already been done.

Therefore, although there are benefits to the use of the Internet for online forums, support groups, and health information, there is still a concern of disclosure for HIV-positive individuals. The experience of receiving an HIV-positive diagnosis may be very difficult for an individual to share, and the anonymity of the online world may be a helpful space for some to express their experiences. A complete openness in telling one's story on an online forum may put one at some risk of judgement, however, the literature mostly demonstrates benefits for the users of online forums for HIV and AIDS, and other health conditions and concerns. The benefits are described in the positive experience of sharing with others living with HIV, the support shared and received, the generally accepting space of online communities for disclosing one's status, and the safety of a common ground from where to move forward in life with one another. Therefore, although online forums may not be the perfect spaces, they are likely to be safer spaces for disclosure than in the offline world.

2.6 Internet access in South Africa and the developing world

In 2012, the fourth national survey for HIV was conducted in South Africa, and the prevalence results released in 2014 reported that there were 6.4 million HIV-positive people living within South Africa (Shisana et al., 2014). The results demonstrated a significant difference between the prevalence statistics in rural and urban areas, with there being a far greater number of people living with HIV in the rural areas of South Africa (Shisana et al., 2014).

Communicating and sharing information is a key focus of required interventions, particularly in areas where there is high prevalence of HIV (Shisana et al., 2014). These interventions can help to inform the population about the importance of knowing about HIV, its implications, ways in which transmission can be prevented, and treatment options (Shisana et al., 2014). The means by which to communicate information about HIV and educate communities are impacted on by the lack of access to technology in rural areas. The Internet is accessed by more than 3.1 billion people in the world, which leaves approximately 4.2 billion people, mostly across the developing world, without Internet access (West, 2015). Individuals unable to connect with others, society and the world, through the Internet, experience great economic disadvantages (West, 2015). Poverty, high costs of data, and difficulties with policies and infrastructure, all impact on access to Internet in developing countries (West, 2015). In South Africa, national survey results suggest that television and radio programmes are the most widely accessed means by which information about HIV is shared, and through which individuals feel influenced to acknowledge the serious consequences of the virus (Shisana et al., 2014). Across all developed and developing countries, there is a need for making use of the Internet, connecting with others online, and searching for information, and therefore there are benefits to increasing access to the Internet.

There are a number of ways in which access can be improved; through lowering the costs of data and telecommunications, growing infrastructure, developing understanding of the digital industry, and creating more efficient networks and lower taxes (West, 2015). Improvements to accessibility will benefit the education and health care industries, through allowing people greater, and immediate, access to information on medication, treatment and advice, for illnesses, through their cellphones (West 2015). Research conducted into cellphone usage in a rural area of the Eastern Cape in South Africa, found that even with a high unemployment rate, between 60 and 69% of individuals living in the area used their phones to search the Internet and for social networking (Dalvit, Kromberg, & Miya, 2014). According to a study conducted by Deloitte into the benefits of increasing and growing Internet access, "Evidence on the link between health literacy and mortality rates suggests that access to the Internet has the potential to save nearly 2.5 million lives across the regions covered by this study, if they were to achieve the level of Internet penetration seen in developed economies" (Deloitte, 2014, p. 4). The regions covered in the Deloitte study were "Africa, Latin America, South and East Asia and India" (Deloitte, 2014, p. 9). This suggests that access to the Internet can have a positive impact on the effects of those living with illnesses, such as HIV.

The findings of this study aim to explore how an HIV-positive diagnosis is experienced. The research explored the experiences as expressed on an online forum, as well as the support that is sought within the forum's support group. The literature reviewed suggests that there may be benefits to accessing social support for HIV-positive individuals, and online support, in the form of online forums, may influence the coping mechanisms and well-being of recently diagnosed HIV-positive individuals. There is a lot more to be learnt about the use, and experiences, of online forums for HIV-positive individuals, and ways in which the benefits of accessing the forums may be more widely known and accessed. The literature suggests that there may be a number of benefits experienced by individuals accessing support, information, and advice online. Through increasing digital accessibility across the developing world, more individuals may be able to benefit from the sharing of information about illnesses, treatment options, medication, advice, and support, from health care providers and other users of online forums, for HIV and other illnesses. Through the Internet in general, and online forums in specific, the experiences of stigma can be mediated for HIV-positive individuals, through the provision of a safe space for sharing with others, and educational interventions to impact on the various forms of stigma that exist in society surrounding HIV, and the individuals who are infected, and affected, by the virus.

This exploratory study is based on two research questions:

- What are the individuals’ experiences, as described on the online forum, of receiving an HIV-positive diagnosis?
- What types of support are sought and offered, on the online forum, for recently diagnosed HIV-positive individuals?

2.7 Conclusion

The rationale for this research lies in the context of the increased use of the Internet for support, communication, and information, for people suffering from chronic illnesses. A number of studies have explored online social support for people living with chronic illnesses, and the use of the support groups for emotional and factual support; however, they do not all focus on one illness (Braithwaite, Waldron, & Finn, 1999; Coulson, 2005; Finn, 1999; Mo & Coulson, 2008; White & Dorman, 2000; Winzelberg, 1997).

Furthermore, exploring the experiences surrounding an HIV-positive diagnosis is of importance, in order to better understand how help may be provided for newly diagnosed individuals. The underlying aspects of coping with HIV include the processes of transforming personal identities and ways of being, as well as gathering support (Burchardt, 2010). Through understanding the experiences of an HIV-positive diagnosis, interventions can be established, and support provided, to manage uncertainty and develop skills for living with HIV (Brashers et al., 2004).

Chapter 3: Methodology

3.1 Introduction

This study investigated the experiences of recently diagnosed HIV-positive individuals, as shared on an online forum. The research has employed an epistemological framework of Interpretative Phenomenological Analysis (IPA) to explore, attempt to understand, and interpret the experience of receiving an HIV-positive diagnosis. This chapter discusses the research design chosen for this study, and details the sample, data collection and analysis procedures, as well as the reliability and validity of the theoretical framework, and the ethical issues considered.

3.2 Research questions

The overarching question framing this study is:

- What are the individuals' experiences, as described on the online forum, of receiving an HIV-positive diagnosis?

An additional question explored for this research is:

- What types of support are sought and offered, on the online forum, for recently diagnosed HIV-positive individuals?

3.3 Research design and theoretical framework

This exploratory study examined the experiences of recently diagnosed HIV-positive individuals, through posts on an online forum. Due to the emphasis of the study being on people's lived experiences, IPA was used. "IPA is a suitable approach when one is trying to find out how individuals are perceiving the particular situations they are facing, how they are making sense of their personal and social world" (Smith & Osborn, 2003, p. 55). As a qualitative research method, IPA does more than describe experiences; it involves an idiographic, phenomenological and hermeneutic interpretation in its analysis (Larkin, Watts, & Clifton, 2006). An IPA researcher has two aims; the first is to try to make sense of the world of the individuals being studied, and form a description of their experiences, and secondly, interpret the descriptions with respect to social, psychological and cultural factors (Larkin et al., 2006). In IPA research, "the sense-making activities of people (in conversations, diaries, group discussions, or other forms) are the basis for learning about their relationship to the world", and from this the meaning of the particular experience for an individual in certain circumstances can be described (Larkin, Eatough, & Osborn, 2011, p. 14).

IPA is idiographic in its analysis, as it is focused on specifics: specific individuals, and often as they manage specific circumstances and experiences in their lives (Larkin et al., 2006). The idiographic nature of IPA with a focus on the unique aspects and experiences of an individual, rather than on populations or large groups, gives the analysis a subjective tone (Smith & Osborn, 2003). Generalisations can be made at a theoretical level with IPA, as commonalities can be found across analyses, personal experiences, and literature, to inform understanding of experiences in the wider context (Smith & Osborn, 2003). In qualitative psychological research, experiences are situated, and "situated' carries the connotation of situated 'in meaning', as much as it does 'in personal and social relationships', and 'in a physical world of objects" (Larkin et al., 2011, p. 2). Individual experiences vary across different circumstances, over time, and according to cognitive states, and the environment, in which one is situated (Larkin et al., 2011).

With its focus on the meaning of phenomena, IPA research focuses on the individual as situated in a context of society, history and culture, as all individual experiences exist in particular circumstances (Larkin et al., 2011).

On an intellectual level, IPA is closely linked to “hermeneutics and theories of interpretation” (Smith & Osborn, 2003, p. 53). Two levels of hermeneutics are involved in IPA, in that the researcher’s role is to attempt to make sense of the participants’ attempts to understand their worlds (Smith & Osborn, 2003). Within this double interpretation, the phenomenological aspect requires the researcher to see beyond the words or text, in order to reach the lived experiences of individuals prior to their conscious expression and reflection (Terre Blanche & Durrheim, 2006). Therefore, with a focus on “being-in-the-world” and “lived experience” as described by IPA research, the phenomenon being studied is viewed and analysed from the perspective of the individuals participating in the research (Larkin et al., 2011, p. 13). The interpretative aspect of IPA reflects the researcher’s role as finding meaning in, and making sense of, the individual’s journey to make sense of, and understand their worlds (Smith, 2004). Interpretation in IPA allows for both critical questioning, and empathy by the researcher (Smith & Osborn, 2003). Therefore, IPA involves a process of trying to understand an experience from the point of view of the individual, while at the same time, critical analysis of the quoted text (Smith & Osborn, 2003). When one is diagnosed with an illness, often there is a sense of one’s identity being vulnerable and a process of self-reflection and finding meaning from the diagnosis occurs (Smith, Flowers, & Osborn, 1997). In this research, the aim is to attempt to find, and interpret what an HIV-positive diagnosis means to individuals in the context of posting on an online forum. One of the philosophies of IPA is a shift in attitude and a focus on being reflective on the everyday lived experiences being researched (Shinebourne, 2011). This shift is to an attitude specifically phenomenological in nature, where the researcher becomes immersed in the participants' experiences of their world, and reflective with regards to the manifestation of this world for the researcher (Thompson & Zahavi, 2007, as cited in Shinebourne, 2011).

The typical data collection process for IPA is the use of semi-structured interviews with a small sample of participants; in order to access the meaning of their experiences as expressed in their own words (Smith & Osborn, 2003). The research design for this study has not collected data through interviews, but instead the data was collected from the posts on an online forum, as it is specifically the online experience that is of interest for this research. Although interviews are the most common data collection method used when the data is analysed with IPA, other methods of collecting text are suitable, as this form of analysis functions with any forms of text that have been produced by individuals in their own, natural environment (Mulveen & Hepworth, 2006; Rodham, McCabe, & Blake, 2009). The use of posts on an online forum is beneficial as the data is accessible and unmediated, and it is reasonably assumed that due to the anonymity of the posts, individuals are able to express their true feelings in their attempts to make sense of the experience of receiving an HIV-positive diagnosis. Although the use of online posts doesn't allow for probing further as one does in semi-structured interviews, this data collection method allows for access to a larger sample of relatively short excerpts. Therefore, using the online posts, the detailed analysis of IPA can be done on short or small samples of experiences, from a larger sample of individuals, which provides an exploration into a number of different lived experiences.

The data collection approach of using online posts has been used as a method with IPA for analysis in other studies exploring individuals' experiences of complex and chronic illness and conditions (Hadert & Rodham, 2008; Rodham et al., 2009). In a study conducted into the chronic illness, arthritis, the researchers explored interactions on an online message board, and analysed the data collected online using IPA, as it allows for the researchers to gain a perspective from inside the different experiences of a group of individuals who are joined together by a shared experience (Hadert & Rodham, 2008). An exploratory study into the experiences of women adjusting to developmental dysplasia of the hip was conducted where the data was collected through an Internet search to access the most active and easily accessible online message boards, and the posts from regular users collected and analysed (Gambling & Long, 2011). Gambling and Long's (2011) study was informed by IPA, as the researchers explored online users' experiences of, and meanings made, around adjusting to living with a chronic condition.

The object of study in this research are the written experiences of the recently diagnosed individuals, and the goal is to engage with and explore the lived experiences of the individuals, and the meanings attributed to these experiences, through their online posts. The online forum used for this research was selected due to the relevance of the threads on the site, as well as the ease of access as the forum is open, and contributions are available to the public. The research design for this study raises some ethical considerations, which are discussed in detail in the last section of this chapter.

3.4 Sample

For this study, a homogenous sample with a specific characteristic and a particular experience was chosen for exploration. With the interpretative phenomenological approach, the study is not seeking to make general claims, but rather report on the experiences of a relatively homogenous sample, in order to identify common themes (Smith & Osborn, 2003). The units of analysis for this study are the excerpts or posts made by people who identify as being HIV-positive, and have described their experience of recently receiving an HIV-positive diagnosis and are seeking support. The sample consists of 140 initial posts made by self-identified HIV-positive individuals across various threads on one online forum. The sample of posts was not chosen according to any other criteria of gender, age, country or race. The posts collected for the study were all recent, having been written on the online forum from 1st January to 31st December 2015.

3.5 Procedure for data collection

The procedure for the data collection involved accessing the forum as a guest and reading the threads as an unobtrusive observer. The 140 initial posts made across various threads on the online forum, between January to December 2015, were collected. The researcher copied the posts from the forum and pasted them into a word document.

3.6 Data analysis

The approach of IPA is concerned with understanding the lived experiences of the participants from each individual's viewpoint, as well as critically exploring and questioning in order to make sense of the experiences (Shinebourne, 2011). The first step of the analysis was to become immersed in, and familiar with the data by reading over the posts. For this process, the posts were copied from the online forum and pasted into a word document. The researcher then printed this document and spent time reading through the posts. During the reading and rereading process, quotes that were of specific interest for the experience explored in this study were highlighted, and the researcher made notes on the side of each page, with thoughts on particularly interesting aspects in the posts, and ideas about possible emerging themes. The excerpts that were the least rich and useful for the purposes of this study, based on the length of the post and the expression of experience rather than figures or facts, were discarded at this stage.

Once familiar with the data, the following step was to begin to look for themes across the data, involving reading the sample of posts a number of times and noting themes of interest (Smith & Osborn, 2003). At this time, the data was copied into a table in an excel document with three columns for the themes, the excerpts and notes. An initial list of themes was compiled and each given a code, and the excerpts were provided with identifying codes as a means of labelling the experiences according to similar phenomena or themes. This process went through a few phases as the themes evolved. Each excerpt was also assigned a number as a form of identification for the findings and discussion chapter. The following steps were taken to make connections between the themes identified according to codes and arrange them analytically (Smith & Osborn, 2003). During the process of compiling the themes, they were checked against the words or phrases actually used by the online forum users to ensure that they were supportive of them. In IPA, the themes are established from the direct words of the individuals' experiences being researched, and direct quotes are used to show that the analysis grew directly from their quotes (Brocki & Wearden, 2006; Pringle, Drummond, McLafferty, & Hendry, 2011). Finally, a small number of superordinate themes were concluded. The themes are presented and discussed in the following chapter, which consists of the integrated findings and discussion for the research.

The interpretative nature of this study involves the subjectivity and reflexivity by the researcher. The process of data analysis for this study initially involved empathic and descriptive interpretations of the lived experiences described in the online posts, and then critical reflection, ensuring that the meaning of the experiences was not lost (Smith, 2004). Therefore, through the analysis process the researcher engaged in reflection, and these thoughts are discussed in the final chapter.

3.7 Reliability and validity

Yardley (2000) describes the essential criteria for strong qualitative research as demonstrating sensitivity to the context of the study, deep engagement and commitment as well as rigour, to be transparent and coherent, and have an impact in its field, as well as to be of importance.

Within the IPA framework, a sample is chosen because of a specific lived experience, and sensitivity to the individual experiences and the understanding of these, is given particular focus during the engagement with, and interpretation of, the data; as has been required in this study (Shinebourne, 2011). The context of this study is embedded in internet-based research, and the use of the online world for chronic illnesses, specifically HIV. Within the context of internet-based research, this study has stipulated specific ethical considerations, and within the context of

HIV, the researcher has engaged in a variety of relevant literature. A diagnosis with HIV often creates concerns regarding confidentiality, and therefore careful consideration has been given to being sensitive to these concerns by ensuring anonymity of the posts in this study. This study is situated in an undefined social, cultural or racial context, as the online posts analysed are not from any particular country or culture or gender known to the researcher. Therefore, in engaging with the online posts, consideration was given to the personal experiences of the individuals in the context of the illness of HIV across the world.

Adherence to commitment and rigour in IPA is achieved through deep immersion with the data (Shinebourne, 2011). Thorough, transparent and appropriate research methods, and analysis, are important in order to produce rigorous research (Tracy, 2010). In this study, the reasons for making certain decisions relating to the research design are discussed, and the researcher engaged with questions regarding the amount of data required and the appropriateness of aspects of the methodological processes. The researcher also committed to ensuring that during the analysis, the original text was continuously consulted in order to ensure that the interpretations made, and themes identified, are representative of the original text in the online posts.

Every person sees the world through a certain lens or perspective, and this influences the way in which meaning of one’s world is made. Therefore, in qualitative research, it is important to acknowledge the influence of one’s own viewpoint through processes of reflexivity that are coherent with the theoretical framework for the research (Saville Young, 2016). In IPA studies, reflexivity is an important aspect of the transparency criterion, and consistent attention is required by the researcher to acknowledge and reflect on the impact of the relationship between the data and researcher (Shinebourne, 2011). In this study, the researcher made notes relating to thoughts about themes, and questions about the experiences described by the online posts, throughout the analysis process. The researcher also described in detail, the data collection and analysis process, and the influence that the aspects of the methodology that were different from a typical IPA study, may have on the interpretation and illustration of the findings. In qualitative research, coherence is achieved through achieving the goals the research set out to do, by connecting the methodology, analysis, and theoretical framework throughout the study (Tracy, 2010). With the research questions in this study focused on the experience of receiving an HIV-positive diagnosis, the framework of IPA allowed for these experiences to be explored in an empathic and critical manner.

Finally, the validity of a qualitative study may be measured by whether it provided the reader with interesting findings and discussion, and a significant contribution to the field of research (Tracy, 2010). This study aimed to provide insight into the lived experiences of receiving an HIV-positive diagnosis. With the availability of online support groups, and online forums, for those living with HIV and other chronic illnesses, the experience of receiving an HIV-positive diagnosis is of interest as it keeps evolving in the context of ever-changing perceptions, accessibility and knowledge.

3.8 Ethical considerations

Internet-based research involves acquiring data from the Internet and other technologies, in essence gathering information in the absence of face-to-face interaction with participants

(British Psychological Society, 2013). This type of research raises unique ethical concerns for consideration surrounding the lack of active awareness and knowledge of participation in the research, and the complicated decisions regarding data being found to be in the public or private arenas (British Psychological Society, 2013). Internet-based research therefore requires the consideration of certain ethical principles taking into account the generally blurred domain of the online world.

Ethical approval was applied for and granted from the Department of Psychology's Research Proposal and Ethics Review Committee (Reference Number: PSY2015/28). The Code of Human Research Ethics stipulates four ethical principles to be considered in conducting research: "Respect for the autonomy and dignity of persons; scientific value; social responsibility; and maximising benefits and minimising harm" (British Psychological Society, 2013, p. 2). The application of these principles to this research will be discussed.

Confidentiality, nonmalificence and beneficence are concerns for ethical consideration in research (Terre Blanche & Durrheim, 2006). The researcher requested for the requirement for informed consent to be waived for this internet-based research. There is no perceived privacy expectation on the online forum used for this research, and particular care has been taken to ensure confidentiality and anonymity. The data used for analysis is deemed to be in the public domain as it can be accessed and read without having to become a member of the site. In a study conducted into the chronic illness, arthritis, the researchers explored interactions on an online message board and noted that the openness of the message boards suggested that it is an environment in which individuals would expect their posts to be seen by others, and as long as confidentiality was maintained, informed consent was deemed unnecessary (Hadert & Rodham, 2008).

Similarly, the online forum used in this study states a privacy warning for its users. The privacy warning emphasises that the forum is open to the public and can be searched and accessed via any search engine. The use of non-identifying usernames is encouraged for the forum users if they are concerned about the confidentiality. In the case of this study, the name of the online forum and the usernames have not been disclosed and therefore steps have been taken to maintain confidentiality and the anonymity of the source of the data. The sample for this study consisted of posts on the online forum, rather than the usernames, and therefore no identifiers from the online forum have been stated in this research. Guidelines recommend that maximum effort be given to procedures to ensure anonymity and minimise the data source being traced (British Psychological Society, 2013). The researcher ensured that careful attention was paid to remove any possible demographic information that may identify the individuals behind the posts.

This study was non-reactive and unobtrusive in its research design, with data being collected passively. The researcher did not become a member of the online forum. If a researcher becomes involved in discussions on an online forum, without disclosing their identity as a researcher, this may be seen as deceptive, and unethical to create a “false” identity. Joining the online forum for the purposes of this study would be intrusive and unethical, as it would require a false HIV-positive status disclosure by the researcher in order to become a member. If the researcher’s identity was disclosed, it may bias the posts and replies on the forum. Joining the forum, and identifying the purpose of becoming a member for research purposes, may cause the other members to change their posts, withdraw from being active on the site, and detract from their experiences expressed as well as their experiences of the online forum.

The nature of the research is deemed to have high value for better understanding the traumatic experience of receiving an HIV-positive diagnosis. The accessibility of the posts on the online forum demonstrates that people may benefit from the information provided on the site, and therefore its availability is maintained, to be beneficial to anyone who is seeking support.

3.9 Conclusion

This methodology chapter explained the theoretical framework and research design for this study, and discussed reliability, validity and ethical considerations. The idiographic, phenomenological and hermeneutic nature of IPA was discussed, and its choice as the theoretical framework for this study, due to its focus on lived experiences. The research design, with the choice of online posts as the sample, and type of data collection method, were discussed, and consideration given to the ethical issues related to the choice of research design, as well as a focus on confidentiality and anonymity. The criteria for reliable and valid research were discussed with specific focus given to sensitivity to context, commitment and rigour, transparency and coherence, and the importance of the findings for the field of research. The following chapter will present and discuss the findings of this exploratory study.

Chapter 4: Findings and Discussion

4.1 Introduction

This research investigated the experiences of recently diagnosed HIV-positive individuals, as shared on an online forum. The research aimed to explore the individuals' experiences, as described on the online forum, of receiving an HIV-positive diagnosis and the types of support sought and offered, for recently diagnosed HIV-positive individuals. Themes relevant to the research aims were identified during the analysis. Although the posts were relatively short, some of the single posts included a number of different themes, whilst others focused only on a single theme, showing a difference in the experiences of receiving an HIV-positive diagnosis and the variety of emotions and thoughts experienced, and expressed by individuals. This chapter explores the themes that emerged from an immersion in the data, and each of the themes will be discussed separately.

There are five identified themes. The first is that of the need for information and advice, and this theme is titled *am I going to be ok?* After receiving an HIV-positive diagnosis, some individuals experienced a need for answers to a variety of questions and concerns for which the medical professionals have not always answered, as a means of reassurance, as well as support regarding the impact of the virus on their life. The second theme is that of *shock, blame and guilt.* The majority of the posts involved a story involving explanations of how the virus was acquired, the shock experienced from the diagnosis, and feelings of blame, guilt and fear amidst the story. The third theme is that of *a rollercoaster of emotions.* There are a variety of emotions experienced following an HIV-positive diagnosis including denial, anxiety, depression and hopelessness. The influence of stigma, and anger at oneself, can impact on an individual's emotional resilience, and an HIV-positive diagnosis can cause suicidal ideation with cries of help for dreams and hopes no longer seemingly possible. The fourth theme is that of *disclosure, support and stigma.* After receiving an HIV-positive diagnosis, a sense of isolation and loneliness is often experienced, and the decision regarding to whom to disclose becomes a lonely battle. The social support that an individual receives can greatly influence the experience of the diagnosis. The fifth theme is *thank you - life can carry on*. The online forum provides a sense of belonging and support, which allows for different experiences to be felt and expressed. This theme reflects the resilience of individuals, as well as the impact of social support and education on the experience of receiving an HIV-positive diagnosis.

As described in the ethical considerations for this research, any potentially identifying information was removed from the excerpts, and a number as a form of identity has been given to each excerpt (written in brackets at the end of each post).

4.2 Theme 1: Am I going to be ok?

The data from this study suggests that there is often a need for information and answers following an HIV-positive diagnosis, which reflects the type of support sought and offered, on the online forum. Groups that offer support can help with feelings of loneliness and shame for individuals diagnosed HIV-positive, as well as allow for empathy to be experienced from relationships formed (Paudel & Baral, 2015).

> “Confirmed Positive Two Weeks Ago - and a little frustrated. Can anyone tell me if these numbers are good, bad, or indifferent? Numbers are CD4 is 327 and viral load last week was 36300. Just a little lost and a lot overwhelmed. But I think I'll make it.” (14)

> “In May I was diagnosed and started treatment with Truvada, Isentress and Bactrim. My numbers were bad. Last weeks results have me worried. CD4 number is still rising and it’s at 197, but the VL is at 200,000. How is that even possible? I have taken the meds religiously every day. Now I'm scared that the treatment isn't working.” (37)

These two posts demonstrate how information, advice and support is sought from the online community in order to feel some sense of calm, and belonging, from others who have been through the common experience of an HIV-positive diagnosis. Receiving support and advice from someone who has also experienced a diagnosis with HIV allows for one to feel understood in a space of shared experiences (Brashers et al., 2017). The online forum posts commonly seek advice and reassurance regarding CD4 count and viral load results, from those who have already started treatment, to assist with levels of anxiety, and seemingly to feel less alone in the confusion surrounding these numbers.

A theory with regards to the management of uncertainty for people living with HIV, suggests that often individuals attempt to manage their uncertainty through efforts to gather as much information as possible about living with HIV, as well as interacting in environments where information can easily be obtained and shared (Brashers et al., 2017). Individuals may seek information due to unsatisfactory and unsympathetic communication at the time of diagnosis. The experience of receiving an HIV-positive diagnosis may be influenced by the way in which the diagnosis is given (Pergami, Catalan, Hulme, Burgess, & Gazzard, 1994). The delivery of the diagnosis in a sympathetic and reassuring manner, as well as the amount and standard of the information provided, impact on an individual’s experience of receiving a diagnosis, as well as their ability to cope following the news (Pergami et al., 1994). Being given sufficient time to ask questions, as well as discuss one's feelings, and being asked about levels of social support are all important aspects in the communication of an HIV-positive diagnosis (Pergami et al., 1994). The online forum is one such environment where uncertainty can be lowered through gathering information from others who have recently experienced an HIV-positive diagnosis, or are living with HIV. Some posts described the experience of feeling concerned about survival, with being HIV-positive, and living a normal life with any potential side effects of medication. The online forum provides a space where worry and concerns may be calmed through sharing, and acquiring support and reassurance from other HIV-positive forum members. The need for reassurance and advice from others who are living with HIV is expressed in the post below.

> "It's hard it really is. I can't believe this happened to me. I recently got put on meds, and they are messing me up. I feel very nauseous and I constantly want to puke all day every day. I'm scared, is this how the rest of my life will be? I need support, I would like to talk to people who are going through/went through what I am dealing with. I need a friend now more than ever." (61)

Findings from studies exploring the access to antiretroviral therapy, indicate that concerns regarding side effects from the medication, as well as the effect it may have on positive mood and self-confidence, and the lack of significant symptoms, influence an individual's decision to start accessing antiretroviral therapy (Gold, Hinchy, & Batrouney, 2000; Gold & Ridge, 2001). Further to information, reassurance and support, regarding symptoms, CD4 and viral load counts, treatment options and medication side effects, advice regarding the impact that a new status of HIV-positive has on one's working life and financial stability, is also sought on the online forum.

> "… I'm a…gay male…. I went to an HIV testing clinic…. They did two blood tests and they both came back positive. I am now kicking myself over why I didn't get tested sooner. It must have been 3-4 years since I last got tested (and was negative). And it must be at least 2 years since I contracted it. I'm just mainly worried I waited too long to get tested…I'm worried about how all this will cost me financially since I live paycheck to paycheck. I'm worried how this will affect me at work since I'm not "out" at work and especially don't want to disclose my HIV status to them. So now I want to look for other jobs…. The people I have told however have been very supportive. The one phrase of support that I heard that is really helping me right now it that I am going to ok." (55)

> "I have been recently diagnosed positive a week back. Currently I am struggling with a lot of questions in my mind. I am grossly underweight, I need to look at the financial expenses involved in the treatment, is it possible to get treatment from private practitioner but take medication and get tests done at reduced rates from the ART centers? How expensive is the treatment in the short, medium and long run…?" (72)

These posts demonstrate that information regarding the cost of medication, and implications surrounding stigma in the workplace may not always be readily available or offered by health care providers. There has been a significant decrease in the costs of antiretroviral medication over the years, which has allowed for treatment to be available to a greater number of HIV-positive individuals (Byakika-Tusiime, Polley, Oyugi, & Bangsberg, 2013). Research suggests that the cost of medication for HIV impacts on an adherence to the medication (Byakika-Tusiime et al., 2013). Therefore, the perceived financial burden of being HIV-positive may increase stress and impact on the coping mechanisms of recently diagnosed individuals.

The financial implications of treatment for the virus are also influenced by different country and medical regulations. With an HIV-positive diagnosis may come fears of not being able to continue working, not being able to afford correct treatment, and not being able to travel and live in other countries.

> "…. Even in job searching, HIV status is for discrimination, and for dating, even many gay people discriminate positive…. So, I have been thinking about emigrating or working in other countries, but cannot sure it is that easy for positive…." (79)

The “National Commitments and Policy Instrument” monitors the laws and policies of different countries with regards to HIV and AIDS, and assists in assessing the aspects of each country’s regulations that impact on the risks of HIV transmission, and the accessibility and availability of services for HIV-positive populations (Torres et al., 2017, p. 1). Information regarding different countries’ policies may not be readily accessible, and therefore an online forum space where individuals from countries all over the world are able to access and share information, may be of great use for interacting and gaining knowledge on the laws of different countries.

The experience of receiving an HIV-positive diagnosis may be overwhelming and confusing, and from this study it seems one of the first steps for many individuals is to seek advice, information and reassurance regarding their medical readings, treatment and finances. Guidelines on pre-test counselling suggest that prior to taking an HIV test, the health care provider administering the test is advised to discuss the individuals reasons for taking the test, the procedure of the test, and its confidential nature (Bell et al., 2016). Guidelines, however, are often lacking with regards to preparing the individuals for the possible social consequences, and discrimination as a result of the HIV test (Bell et al., 2016).

The World Health Organisation’s guidelines for HIV testing state five principles by which all testing should be done: informed consent, the confidential nature of the test should be confirmed, counselling should be offered to all individuals allowing an opportunity for questions to be asked, surety of a correct diagnosis, linking the individual to further information, and providing follow-up for support regarding treatment options and other services of care (World

Health Organisation [WHO], 2015). An individual's health following an HIV-positive diagnosis is influenced by the sense of empowerment experienced to make decisions informed by information regarding treatment and care options provided by the health care provider administering the test (WHO, 2015).

Guidelines advise that post-test counselling should be centred on the individual and their specific personal circumstances, questions, and requirements (WHO, 2015). Post-test counselling following an HIV-positive diagnosis should include the following: an explanation of the results; discussion on the availability and levels of social support; provision of information on antiretroviral treatment, and ways in which to prevent transmission; the process and challenges of disclosure; an assessment of the individual's emotional state and risks of depression and suicidality; referrals for counselling and other services; a specific date and time of referral for follow-up HIV care; and importantly sufficient time in which to ask questions (WHO, 2015). However, the shock experienced following hearing an HIV-positive diagnosis may impact on the ability of an individual to absorb and understand the information provided immediately following a diagnosis (WHO, 2015). Therefore, follow-up sessions may be beneficial for individuals in order to allow them a further chance to ask questions, and be provided with information and support (WHO, 2015). The shock experienced following an HIV-positive diagnosis may impact on an individual's ability to absorb the information provided by health care providers (if the correct guidelines have been followed), and the online forum may then become an important space where information and support can be obtained once the initial shock has begun to subside.

Adaptive coping strategies that focus on approaching adversity in order to learn, gain knowledge and problem solve can have a positive impact on overall well-being (Penedo et al., 2003). The coping strategy of taking direct action to seek social support, advice, and information following an HIV-positive diagnosis can positively influence emotional and physical health (Moskowitz et al., 2009; Penedo et al., 2003). Therefore, the availability and use of online forums to access information and support from other HIV-positive individuals, as well as the active involvement of individuals on the forum, may help to encourage approach-oriented coping strategies and enhance positive coping following an HIV-positive diagnosis.

4.3 Theme 2: Shock, blame and guilt

Findings from this study suggest that feelings of shock, blame, guilt and also betrayal are common threads across the diagnosis experience. Through describing or explaining how the virus was contracted, personal stories are formed around a collective understanding.

One of the overarching emotions experienced and expressed on the online forum is that of shock, in the sense of disbelief that the virus would ever become part of one's story. Shock, fear and lack of belief are common emotional reactions experienced following an HIV-positive diagnosis (Treisman, Jones, & Shaw, 2014). The experience of receiving an HIV-positive diagnosis may be distressing and overwhelming, and the shock experienced immediately afterwards may make it difficult to distance oneself from one's emotional, psychological and physiological reactions, as expressed in the post below (Gosselin et al., 2017).

> "I was just diagnosed yesterday. After a small breakdown at the doctor's office, and another a few minutes after getting home, I've felt calm, maybe a bit numb too and still in shock but I feel I just need to accept this as quickly as possible because I really have no

> other choice but to accept it and remain calm. Still a lot of other emotions swirling around but I just keep trying to stay calm...” (99)

Some individuals expressed how well their lives were going, how happy and successful they were with the thought that they were invincible to HIV.

> “I was at home preparing for finals.... I wasn't even nervous, so was all the more stunned when I saw the results. A vortex of emotions followed. I took a few days off work and literally sat and cried in a park on and off while trying to remind myself to live in the moment. I'm a gay guy...and from the outside, it looks like I have my stuff together. I have a good career and an amazing network of friends in my city.... I haven't been able to get this off my mind. I need to know that others have overcome this and found great husbands/wives/partners or been able to date successfully.... I'm lucky there are people like you who support others who are going through this painful process. Like others who have posted on here, there are days that I feel totally fine and days, like today, where I can't see the hope even when I squint and tilt my head.” (27)

The above post ties the emotional reactions of shock and disbelief together, with some disappointment, and an overwhelming sense of the perceived impact that HIV will have on the individual’s life.

The experience of shock may be impacted on by the complex mix of risk and responsibility, where an HIV-diagnosis may either be expected due to one being actively aware of the risks of certain behaviours, or a complete surprise where the conscious connection between risk and outcome hasn’t been internalised. The link between one’s own behaviours and the risk factors for contracting HIV can be disconnected, with a sense of invincibility (Schwartz, Block, & Schafer, 2014). The sense of invincibility is expressed in one post, and the shock of the reality of having to take responsibility for one’s behaviours is expressed in the other.

> “I was like what?!?!?...I go to the clinic and lab scientist who gave me the results had this sorry look on his face which totally gave it away before I even looked.... Still wondering how I was able to make it back home in the car driving myself. I didn't expect to see that, but I wasn't surprised either because I had a couple of randoms without protection, always thought it could never happen, how silly of me. It was difficult to disclose to

> anyone particularly because the country I come from the stigma against this virus is still rising high. I fell in to a depressive phase for about a week, but when I found this website and other peoples stories, it gave me a form of relief that I'm not alone…. So just wanted to share my story, hopefully we could motivate each other here. I find this a really good support system besides my parents and siblings." (106)

> "Shocked and helpless don't even begin to cover my current emotional state. My stupid ass also got my partner of 4 years infected too. I feel horribly guilty. I'm just so lost and don't really have anyone to talk to outside of our relationship...." (43)

The data suggests that at times, the individual is consciously aware of the risks of certain behaviour, and has always feared contracting HIV, but felt that the fear would never become a reality.

> "So here I am…. The horrible night I found out I was infected I told my boyfriend. He initially dumped me and left…as it was all my fault (I got infected in a trip I made with some "friends"...got really wasted at the bar and had unprotected sex). We are currently back together and his initial tests (had two fourth-generation) turned negative. I am crossing my fingers for his following tests to go negative as well. Numbed (or was it shocked?) by the news…. One thing I can tell and conclude with. The rules changed; giving up is never an option." (101)

As discussed in the literature, individuals may anticipate being discriminated against if they are HIV-positive, in the form of "anticipated stigma" and therefore engage in maladaptive and avoidant coping mechanisms of denial and disengagement even before receiving a diagnosis (Earnshaw & Chaudoir, 2009; Earnshaw et al., 2013; Turan et al., 2017, p. 284). This fear of a possible HIV-positive diagnosis sometimes prevents individuals from getting tested, and at times it may seem easier to continue living in denial, even with possibly experiencing symptoms, than have to face an inevitable truth, as described in the post below (Schwartz et al., 2014).

> "Allowed myself to do acts that put myself and my partner in danger. The more I did the more I wanted. Things weren't that great in my relationship so I allowed myself to sink into a dark place. My inkling of being HIV positive came when I felt my body run down. I went to get tested and results are surely enough positive. Why did it take so long for me to get tested knowing the fact that I could be positive? I was mentally preparing myself and getting my mind ready for what's to come. In hindsight I should have got treatment

> earlier. I guess I was also afraid to. I have grown a lot from where I was and I learnt to take care of myself and think about those around me. I guess you learn many lessons in life and know not to do it again. I wish everyone with recent diagnosis all the best, things will be okay learn to love yourself and take it one step at a time." (4)

With stereotypes and stigma around sexual orientation and the physical look of someone who is HIV-positive, despite being educated about the virus, individuals' perceived risk may still be out of proportion to their actual risk of HIV (Schwartz et al., 2014). As described in the post below, the shock of receiving an HIV-positive diagnosis can create a sense of there being no future for them, and that their perceived future has now been destroyed (Okoror, Falade, Walker, Olorunlana, & Anaele, 2016).

> "Who would have thought that a standard checkup at my new doctors would result in receiving the worst news of my life.... I walk in the office and the doctor spills the news, you're HIV+. I thought my life was over.... I still haven't told anyone and not sure if I will anytime soon. I know I am not dirty or any less of a person than someone who is HIV- but I can't get this idea out of my head that I am damaged goods.... Thanks for listening" (126)

An expression of blame can be found throughout the online posts, either directly or indirectly through exclamations of disbelief. When diagnosed with a chronic illness, individuals often go through a process of judging their own perceived control over contracting the illness, and assigning responsibility to themselves through self-blame, or blaming another for understanding the potential consequences of their actions (Callebaut, Molyneux, & Alexander, 2016; Mantler, Schellenberg, & Page, 2003). In the online posts in this study, the blame is often directed at oneself for allowing transmission of the virus to happen. Literature suggests that individuals, who blame themselves for contracting their chronic illness, will experience distressed psychological and emotional well-being (Callebaut et al., 2016).

> "I was scared. I was full of guilt. I was angry with me. With him. With life. I was there, too. In a place of self-hatred, self-loathing, self-destruction. I was there… Trust me…" (18)

In some of the posts, the blame is directed towards a partner who betrayed trust and knowingly infected their partner, however, even within these posts there is an underlying tone of the process of judging their control over the situation, and elements of self-blame can be felt. The experience of receiving an HIV-positive diagnosis may be felt as the physical pain of being stabbed, shot, as the integrity of one's body has been attacked (Weait, 2001).

> "I just found out about my status last month when I went for a normal check up. I am devastated. I mean all my life I have resisted all the temptation to play around despite being alone. You see, the man who claimed to love me did this to me and I am sure he cheated on me last year and acquired the virus. Am in pain. My biggest challenge now is having support because am not ready to open up to my friends and family." (87)

The process of blame is a psychological interpretation that includes acknowledging the reasons for the outcome having happened (Mantler et al., 2003). With HIV, the sense of agency and active or passive involvement in the behaviours that caused an individual to contract the illness, impact on the perceptions from others, as well as the feelings of blame and responsibility experienced by the HIV-positive individual (Mantler et al., 2003; Nisbet & McQueen, 1993; Schellenberg, Keil, & Bem, 1995). In the following post, the process of judgement of perceived control has resulted in full responsibility being assigned to another person.

> "…. I got HIV from my ex-fiancé…. We dated happily for…years, first six months only protected sex. Then we got tested, both negative and even continued with protected sex for another 6 weeks and repeated test to rule out all risks. Long story short, 2 months before our wedding, found out he had been back and forth between me and his ex for almost a year, unprotected sex with both us. The ex contacted me, which is how I found out…. I rushed my fiancée to take a rapid test. He tested positive. I tested negative. He contacted the ex and she tested positive too. Of course, the rest was fighting not too much about HIV but more about the betrayal. He was devastated with dx, confirmed later with Western Blot…. I concluded I took all precautions but it still happened, I had no control over his behavior out of our bedroom…. My health is fine but emotionally I'm exhausted

> with the betrayal and this type of evil behavior…. Thanks for reading and the great support you're providing here." (124)

With the action and expression of blame by HIV-positive individuals can come the feeling of guilt. Guilt is seemingly one of the most apparent emotions experienced as a result of receiving an HIV-positive diagnosis: guilt for getting infected and sometimes infecting others. In describing the experience of guilt, the online posts in this study suggest that transmission of the virus is often due to engaging in a single act that can never be reversed. The experience of guilt, self-blame, blame and responsibility, when the virus is transmitted through a sexual act, is a complex process, described poignantly in this legal question; "what is the process by which transmitting a virus during sexual intercourse becomes defined as a wrong whose perpetrator ought to be punished?" (Weait, 2001, p. 447). The strength of the feeling of guilt may make one feel as though punishment is deserved, and a sense of hopelessness experienced. The online forum environment is important as it functions as a space for shared, and collective, understanding and where requests for empathy and support are sought (Pfeil & Zaphiris, 2007). In the online community, understanding is sought and offered in subtle ways (Pfeil & Zaphiris, 2007). This is demonstrated in the following post.

> "We were shocked and devastated…. I have been reading many of the posts on here and they have helped me feel less isolated and afraid…. I am having a hard time with the guilt of knowing that I most likely infected my partner." (11)

Linked to the experiences of guilt and blame is the question of forgiveness for betrayal that is described in some of the posts. It seems that support is sought from the other online forum users for advice on how to forgive the person who infected the individual, as well as how to forgive oneself for becoming infected.

> “.... I am struggling with accepting it every single day. I never cheated on him, no drugs, no blood transfusions, nothing. So I know he had to have slept with someone else or did something to give me HIV. I want to move on and deal with us both being positive but I want him to stop lying already. What makes matters worse is that for some reason I feel like he likes men. I have no idea what to do. My worst fear is my family finding out or anyone finding out. I get so sad and feel so hopeless.... I go to school and work full time. Good head on my shoulders. I just don't understand why this happened to me. I pray for strength but it's so hard. Has anyone forgiven their spouse for infecting them? How did you do it? How do I move on and forgive my fiancé and accept this?” (25)

One online forum post described the feeling of finding out they had been walking around being HIV-positive for years without knowing it as they had never experienced significant symptoms to warrant feeling the need to be tested. The shock, guilt, and worthlessness experienced in this post are possibly exaggerated by the delay in the diagnosis, and the sense of previous behaviour unknowingly impacting on a current relationship. However, one of the important aspects of this post is the possible positive effect that the support of a partner can have on mental health and coping mechanisms following an HIV-positive diagnosis. This post implies the importance of educating for regular HIV testing, and interventions to encourage and provide available and accessible HIV testing services.

> “First of all thanks to everyone for contributing to these forums. It's helpful to know that I'm not alone and there are such compassionate people out there willing to help. I tested positive about 10 days ago and struggling to keep it together. So many questions, fears, worries. I can't understand how it happened, when I was single, I was always so careful, even to the point of paranoia. Then about a month ago I started to feel bad, aches, fatigue, headache. At first I think it’s just the flu or something, or maybe stress from my job. But something wasn’t right, worst fever I’ve ever had, and night sweats. After a week or so I’m mostly back to normal, and I might have just blown it off, but I just have this feeling, so I get tested and it comes back positive. I was in total shock. How could I be carrying this around for 16+ years and not know it? Is it now too late for me to benefit from all the treatments that are available these days? Am I a ticking time bomb? Will I get seriously ill soon? I feel worthless, ashamed, stupid. And the guilt of putting my partner at risk all these years… it’s all nearly unbearable. I can’t sleep. I can’t focus on my work. Through everything, my partner has been so wonderful though… supportive, upbeat, non-judgmental. I don’t deserve him. I imagined I might lose him and everything....” (113)

The traumatic event of receiving an HIV-positive diagnosis is often experienced with psychological shock, as well as the emotional shock of the perceived loss of who one used to be and who one had planned to become. Implicit within this theme is the process of assigning responsibility to oneself through self-blame or blaming another for the transmission of the virus, and the feeling of guilt that accompanies this process.

4.4 Theme 3: A rollercoaster of emotions

The experience of being on an emotional rollercoaster is made reference to in a number of the online posts. It seems that a plethora of emotions is experienced in the minutes, hours and days after hearing an HIV-positive diagnosis, as the individuals' mood swings among different states, from shock to hopelessness and many in between. It is these emotions that seem to bring individuals to the online forum.

> "So here I am; not knowing where to start, constantly writing and deleting words that I would not like to be writing nor deleting; thinking about concerns I did not have a few months ago, riding emotional roller-coasters. I think I should start by sort of removing the mask, facing the truth and telling the world (at least this tiny, little, beautiful world of people at the forum) that I am HIV positive…. I still can't handle entirely the fact that my life has changed, that it hasn't, that I am afraid, that I'm brave; that I'm alone, that I have you…. One thing I can tell and conclude with. The rules changed; giving up is never an option." (101)

The emotions expressed in the online posts suggest that the traumatic experience of an HIV-positive diagnosis may be associated with the five stages of grief: "denial, anger, bargaining, depression, and acceptance" (Horter et al., 2017; Kübler-Ross & Kessler, 2005, p. 7). As is common with grief, the emotions may be experienced in waves, up and down, similar to the rollercoaster described in this study. There is a sense of mourning the loss of one's previous life and dreams before the diagnosis, and anger, denial and depression seem to be commonly experienced, as well as acceptance which will be described in the final theme. As described in the association between an HIV-positive diagnosis with the experience of grief: denial, anger and depression are all described in the post below.

> "I don't know what to say first because I'm very emotional right now, denial, anger, fear, frustration, depression etc. all negative emotions you can think of. I was diagnosed last month of HIV, my world collapsed the moment I knew my partner was positive, well at first I'm still hoping that my test will be non-reactive but alas…. And then, last week I caught my partner (ex) that he knew his condition years ago, I was really devastated because I never thought that the person I loved and cared did this to me. I don't know what to do." (63)

Loneliness, fear, and feeling overwhelmed may be experienced following an HIV-positive diagnosis, and the online forum community, therefore, is a space where feelings of loneliness may be reduced, through hearing others share their similar stories. The sense of feeling afraid following a diagnosis, as described in these two posts, is connected to the fear of the unknown and uncertainty (Houtsonen, Kylma, Korhonen, Valimaki, & Suominen, 2014). In the review of literature, the theme of fear permeates the experience of an HIV-positive diagnosis through a fear of so many aspects: the virus, medication, discrimination, stigma and disclosure. This permeation is reflected in posts describing feeling scared of everything.

> "Just diagnosed today, it's been a rollercoaster of emotions. I feel lost, scared, yet wanting to be proactive about everything. I don't know. I've only told one friend and that was after being diagnosed earlier today. I can't/don't want to tell anyone else. I booked a doctor's appointment for next week and want to get the treatment ball rolling. I just hope my mental state will be okay for work next week." (59)

> "I tested positive few days back. I have read an overwhelming amount of information in past couple of days. I am scared of every possible scenario that could go wrong. I am scared of HIV, scared of medicine side effects, scared of finding a good doctor…. Past few days have been a roller coaster for me mentally. I go from lowest depressed state to feeling slightly hopeful again. Mostly it's been sad and gloomy." (21)

Physical symptoms are also reported on the rollercoaster, as the online posts include experiences of individuals' hearts sinking immediately after receiving the news, feeling numb from the trauma, and crying both immediately and for days afterwards. The early experience of an HIV-positive diagnosis may also impact on the stability of one's emotional state and moods may change rapidly as one is processing the impact of the diagnosis on one's life.

> "We did the usual tests. It felt like a lifetime. I'd forgotten my phone so couldn't keep myself distracted. I'll never forget that moment. My heart sank and he told me to sit down. I could feel the blood in my body. Every pulse. Every valve open and close. It made me feel sick. All I felt was numb. We talked and he said he'd rush the results and see me in two days. I don't remember driving home apart from slamming to halt a red light. At which point a few tears rolled down my cheeks. I couldn't cry otherwise I'd definitely crash. I just lay there. Back on the bed, looking up to the ceiling. Nothing running through my head. I felt like I had died. An empty body lying, staring into the obis. It got dark and I just got into bed…." (29)

The findings from this study suggest that on the rollercoaster of emotions following an HIV-positive diagnosis, panic and anxiety may be experienced, and may be influenced by the overwhelming sense of being alone in the trauma, and thoughts of the impact the diagnosis will have on one's life. It seems that the diagnosis is an individual experience affecting one so personally that thoughts about the number of other people being diagnosed everyday or living with HIV cannot be contemplated, or assist to calm the anxiety, when stuck in the shock of the diagnosis.

> "…. Talked to the DR on the phone and he explained everything to me…. I burst into tears and was having bad anxiety, chest pain etc….. been hell and seemed like everything just came crashing down all at once. I was lost, confused, and alone." (48)

The experiences expressed in the online posts suggest that following a diagnosis, fear and confusion may be overpowering, and experiences of depression, and hopelessness, shame and anxiety are described. The online forum provides a space where the fear of the illness may be calmed. Encouragement, support and reassurance can influence an individual's process of accepting their new HIV-positive status, and helping them to feel hopeful about living with HIV (Horter et al., 2017).

> "Been told I am positive yesterday and I need to scream it our somewhere.... I want to cry; I feel this pressure inside of me that most of the times I just can't breathe. I really want to cry but tears won't fall. I want to tell my dearest friends but I can't. I want to tell my siblings but I can't. I feel that it is my burden, that it's not fair to make them feel sad but I just need some comforting words. I think that would suffice for now, until I get stronger and can ask someone for a hug.... I am so sorry!!! I am babbling, is that normal??? I have all of these questions in my mind and suddenly a big empty space pops out of nowhere, and I would be looking at the computer screen for 10 minutes, without realizing its been 10 minutes. I am scared. I'm realizing that my plans have to change. My future became hazy and shady and I just don't know what to make of it. I am just hoping for something better in the next few days.... I'm hoping that I will finally get some sleep, even just for a few hours. But for now, I guess, I am just hoping for some kind words." (107)

The psychosocial influences of stigma and loneliness impact on the development of depressive symptoms amongst HIV-positive individuals (Grov, Golub, Parsons, Brennan, & Karpiak, 2010). Depression is described in the post below, where feelings of worthlessness, shame, crying, isolating oneself, and hopelessness have impacted on financial stability and the maladaptive coping mechanism of using of substances. The post below demonstrates how the online forum may be the first place where people turn following a diagnosis, and a first disclosure on the online forum, with an expression of desperation, can be the beginning of one attempting to gain some mastery over the diagnosis.

> "This is a long story and.... Mentally I'm a complete wreck, I haven't told anyone except a few medical people. If I think about it too much I start to cry, I've been crying while I've been writing this post. When I go to the clinic sometimes I have to hide in the toilets and cry. It hurts to think about it, I cry sometimes after I take my pills. I stopped taking my pills for a bit shortly after I started treatment because I just couldn't think about it and would start crying each time I took them. I spend a lot of time just trying not to think about it.... I haven't told my family. I've let myself become completely alone. I've stopped taking my medications three times so far....the third time was on a drinking bender and just forgot for a few days.... I didn't expect dealing with this to cost so much

> money and take so much time! I haven't been able to find anything new so money is even more tight than usual...If I'm being honest I've been looking for any excuse to just stop taking my meds and go back into denial…. I'm miserable, broke, sick and not managing things very well. I think I was happier when I was just waiting for it to all end instead of actually trying to fight for myself….” (42)

Following the news of an HIV-positive diagnosis, hopelessness is commonly expressed in the posts on the online forum. There is a sense that due to the stigma surrounding the virus, individuals post on the online forum as a cry for help and expressing suicidal ideation due to fear of being discriminated against, living on medication, and having to think about disclosing their status to family and friends.

> “First, thanks for this forum. It gave me a little bit of light in my darkest tunnel. I was diagnosed two months ago…. Before I got deported, me and my boyfriend had a serious conversation on how he would support me and he even planned to go back home with me after six months and build a new life together. Fast forward, he just told me now that he can’t share his life with me anymore. I was in complete shock! He pointed out reasons like he doesn’t want to catch the same illness from me, he's got lots of dreams, he's feeling hatred now and much more. I thought, how can he just left me alone? Life is tough and I am even looking for ways to end this all. I just cant, I don’t know. I’m so lost.” (120)

> “I literally haven't been able to function right since I've found out. Just constantly thinking about it, what happens next, how am I going to live with it, how am I going to tell loved ones, have felt like the world was going double time and I was just an observer. I have so many questions and no idea where to begin asking them….” (28)

Perceived psychosocial, emotional and physical factors impact on suicidal ideation, due to discrimination, isolation from one’s community, ability to cope with the symptoms of HIV and one’s emotional resilience (Carrico et al., 2007). Suicidal ideation following an HIV-positive diagnosis is common, however, these thoughts often subside as resilience and social support increases, as well as understanding of treatment regimes and knowledge of how to live with HIV (Li, Tucker, Holroyd, Zhang, & Jiang, 2016). In the following post, disclosing to a parent was received more positively than expected, and the support that followed the disclosure seemingly helped the suicidal ideation immediately following the diagnosis, to subside.

> "She stated that a faint line appeared on the test, and I had to be confirmed via a second test. I tried to take my life that day. I was going to drive off an on ramp into a ditch, but glad I was just able to get home. I told my mom everything. I came out to her when I was 13 which I thought was tough but by far this was the toughest. When I got home it hit me like a ton of bricks. My mom just being supportive hugged me." (30)

The experience of hopelessness is powerful in the posts below, where the sense of contemplating a life with HIV is seemingly too difficult and painful to comprehend, and the fear of the unknown future with HIV seems overwhelming.

> "I feel hopeless and that my life has come to an end at a very early age, is going through this really worth it? I feel 100% healthwise, do I really need to start going through with this? How much medicine will I probably be taking? Should I get another test done elsewhere?" (26)

> "I am HIV positive, I just want to die. I don't know how I will live, earn or survive. I don't want to live my whole life on medicine, just want to die and end this torture." (20)

In the above post there is a direct cry for help from the online forum, an attempt to be told by those living with HIV that there is a chance at a life that is worth living, beyond the diagnosis.

> "Hi all. I just tested positive…. It's been a rough couple of days for me. Seemed like my mind was only focused on the negative things of this and I would cry nonstop. I couldn't even bring myself to say the word HIV without crying. I was close to suicide on Friday and the caring lady on the suicide hot line helped me get through it. Its now been 4 days since diagnosis and I have been sleeping a lot this weekend, figuring that the more I sleep, the less time I will be awake to think about this. It's going to be difficult, but I hope to get through this initial stage and get over the shock and fear of what is to come. I keep telling myself, I didn't deserve this, as none of us do, but I must focus on the future and stop dwelling on the past…." (110)

Even with having experienced suicidal ideation, approach focused coping mechanisms involving engaging with support systems available such as helplines, may be beneficial in the process of accepting an HIV-positive diagnosis (Penedo et al., 2003).

Part of this feeling of wanting to end one's life is the anger directed towards the self, as some posts describe how even being educated about HIV and having all the knowledge about transmission risks, individuals still put themselves at risk and got infected. This anger speaks to the invincibility discussed in the previous theme, that all the knowledge in the world cannot always save you from harm. However, amongst the anger are feelings of hopelessness and loneliness. It is seemingly clear that knowledge about HIV is not enough to manage the loneliness experienced by HIV-positive individuals, as the anger at oneself, and regret, can seemingly make one feel utterly alone.

> "Tested positive 2 weeks ago. I'm in shock. I even work in the medical field so I know about HIV and I was still stupid enough to be irresponsible and let myself get infected. I'm not good at taking pills. I fact, I hate taking medicine. The thought of taking pills the rest of my life worries me. What if I forget or just give up? I'm so afraid of screwing this up." (81)

Specifically in the below two posts, the experience of depression is described in the sense of wanting to go into a "dark hole" and not knowing when one will come out of it or be able to feel different again. Interestingly the questions to the online forum regarding the feelings going away, and the chance of a normal life again suggest attempts at proactive coping.

> "…. I feel so many things. Sad, lonely, depressed, anxious, powerless, ashamed, low confidence, hopeless. I know that this is a disease that can be well controlled with medication. And I know many people with HIV that are healthy and are living fulfilling lives. Yet I feel like crawling in a dark hole and dying. Is this going to pass? Are these feelings part of the journey that I just need to feel and deal with right now.... I have always been good at pretending everything is ok when on the inside I feel alone and afraid…. I am afraid of being alone. Afraid of getting ill and dying. I suppose that these feelings will become less as time goes by. But it has been very difficult the last month. I am hoping by being a part of this group and forum it might make it a little easier." (77)

> "…. I have not been the one opening my own mouth and saying I am not doing good, and I need help. They know I have a touch of depression, but I did not tell them how bad it was, because I did not want to admit I was really depressed. I put on the smile and did what I had to do. I didn't want to admit I had issues with depression. They knew I had some issues with some insomnia, but I don't know what a full night of sleep is

> anymore…. The depression has gotten a lot worse, my feet and hands still hurt, the insomnia is still there, as well as the fatigue, and malaise…. The thought has crossed my mind, stopping medication, and letting the virus and nature take its course….” (97)

The process of moving from denial to acceptance of one’s HIV-positive status may occur through initially beginning to acknowledge and understand the reality of the circumstances, and as the denial reduces, the experience can start to become integrated into one’s understanding of HIV as part of one’s life (Weaver et al., 2004). Accessing social support may assist in the process of integration of understanding the experience of HIV.

> “.... I heard a rumour about a person I hooked up stating that he has HIV and it’s not a false rumour. Instantly my heart dropped to my stomach, I was very scared and nervous…. I walked into the room she told me to sit down as she grabbed the test along with tissues, she looked at me and said ‘it came back positive’ those words echoed in my mind and my body went limp, falling over in my chair in complete devastation crying ‘I can't believe this!’ She said we have to take your blood to confirm it, at this point my sadness turned into anger…. The car ride to my parents house was horrible! I got to my parents house, walked inside and let a horrible blood curdling scream out as I dropped to the ground, crying and screaming, yes I was very dramatic about this, my mom was screaming what happened I couldn't even speak, when I finally could I grabbed her hand and I said ‘mom I'm sick’ ‘I have HIV’. She was quiet. I couldn't control my emotions and couldn't stop crying my dad came home while I was freaking out, so told him, he started crying, god it was the worse experience of my life. My parents told me they were there for me which helped me so much, I went to my apartment and told my best friend…her reaction was to just start crying. I also told my other roommate and other best friend, each of them cried but are my supporters! I don't know what I would do without them….”(68)

The data suggests that a plethora of emotions is experienced on receiving an HIV-positive diagnosis, and individuals use the online forum as a place to express these emotions and ask for help both directly and indirectly, developing effective and adaptive coping strategies.

4.5 Theme 4: Disclosure, support and stigma

The themes of social support and the stigma surrounding HIV were discussed in the review of the literature, and disclosure of an HIV-positive diagnosis is highly influenced by the stigma surrounding the virus, as well as the types of support expected, and experienced, by individuals.

Psychosocial factors and social context impact on the feelings and actions surrounding disclosure and anticipated stigma (Okoror et al., 2016). The online forum seems to be a space for first or second disclosures, and the online posts include statements regarding whom the individual has told, and advice on how to disclose further. The process of deciding to whom to disclose one's status is described as "overwhelming" and there is a strong desire to have someone to speak to about how one is feeling, and be open about one's HIV status. The online forum serves as a platform to disclose and seek support and encouragement from others who may have had positive disclosure experiences.

> "I was so angry at myself and probably still am. I feel like I failed myself. I definitely feel numb in some ways. I've had to stay busy. I've made the decision that I need to pretend that I will be ok until I get my head around accepting and believing that will be the case. I told my ex, I told a friend, and I told a friend who's an HIV specialist. I've started my partner notification but that has been overwhelming so I think I might have my case manager assist me with that. I've managed to maintain my humour to a certain extent and I know I'm still the same person I was before. I am hopeful but this is…overwhelming at this moment." (84)

The following post expresses the barrier that HIV can cause within one's relationships, due to fear of the outcomes of disclosure.

> "So I just got my results today and found out I'm positive. I have this knot in my stomach and can't sleep. I can't tell my friends or family, I really want to tell my dad because we have become close over the years but he is very old fashioned. I just want to talk to

> someone and tell me its ok that my life isn't over. Because I can't help but feel like it is. I just wish I knew how to tell my family…if anyone has any info about HIV that think would help that would be great, thanks" (122)

The literature review discussed the different types of stigma experienced by HIV-positive individuals, and the impact that stigma can have on the process of disclosing one's status. Intrapersonal or internalised stigma is experienced as self-blame, where one feels ashamed for the perceived way in which their identity will be judged by society due to their HIV-positive status (Okoror et al., 2016). These feelings of shame are connected to the fear of disclosure felt and shared in many of the online posts.

> "…. I told my parents the first day I found out and they understand everything and accepted me as I am…. I'm still afraid and I don't ever plan to disclose my status to anyone in the near future. I fear the stigma and how people will react…." (74)

Internalised stigma involves the internalisation of negative beliefs and attitudes towards HIV, which result in feelings of self-blame and shame (Earnshaw et al., 2013; Okoror et al., 2016). Once stigma has been internalised, it can become anticipated stigma, which creates expectations for, and anticipation of, negative responses from disclosure, and impacts on an individual's experience of themselves and their behaviours (Deacon, 2005; Okoror et al., 2016). The negative beliefs and feelings of shame experienced with internalised stigma may be associated with particular signs of physical health, as described below (Earnshaw et al., 2013).

> "… I just feel really dirty, broken, diseased, sick, ashamed, really ashamed, worthless. I feel infectious, I feel weird in public like people can see that I have AIDS. I haven't dated. I haven't told my family. I've let myself become completely alone…." (42)

Stigma contributes to the way in which an individual appraises an HIV-positive diagnosis, and enacted or present stigma can potentially increase the trauma experienced by an individual from receiving an HIV-positive diagnosis (Zeligman et al., 2017).

> "Thought I would finally post after lurking for the last month and half after testing positive. What a life changing result that was. There are days it seems unreal. I know everyone goes through this and I know it will get better, just wanted to get it off my chest and share with someone. Living in a small rural town there is no one here even to share with without the risk of everyone knowing before I want anyone to know. Now just to figure out how to tell my family." (102)

Stigma exists within society, and beliefs about stigma may exist within individuals due to the thoughts and attitudes one hears amongst one's community. Interventions aimed at encouraging discussions about HIV, and educating communities are important to help reduce stigma and mitigate its consequences (Brondani et al., 2016). However, the means by which the educating is done may not always be effective and beneficial, as described in one post whereby the experience of receiving an HIV-positive diagnosis seemed more traumatic due to previous education about the virus, and confused perceptions regarding the physical features of an HIV-positive person.

> "So, it's officially been a week since my confirmed diagnosis. This is all so overwhelming, it's all I can think about right now, it's consuming me, I'm struggling to focus and I'm really trying hard to just keep at it. Some days are better, some are worse. My GP broke the news to me…my head was spinning, I broke down. All I could see in my mind was the images of HIV I was exposed to growing up. They're not pretty. I've tried to do as much research as I can on my own, but I think I need to stop, the constant search for information is driving me crazy…." (114)

Some posts described how expectations of discrimination were unfounded as individuals had positive experiences of disclosing their new positive status to a family member or friend, and encouraged other online forum users to disclose to close family or friends. This suggests that by overcoming anticipated stigma, there can be improvements to one's health and well-being following an HIV-positive diagnosis (Earnshaw et al., 2013).

> "…. I contacted the two people I had sex with in the 2 - 6 week window prior to starting seroconversion. Fortunately they tested negative. These were my first disclosures and the reactions were quite different. A 25 year old…was so empathic it took my by surprise, even before his own negative result had come in. Conversely, a…45 year old not once

> showed any concern for the difficulty I was going through and seemed angry at me. As far as disclosure I've talked to two sets of very empathetic friends…. Thanks everyone, I really appreciate your support!" (112)

> "Myself and my partner newly diagnosed…. I've also been much less stressed once I told a few friends about my/our diagnosis (and so did my partner). I knew we had a good support network but it was still scary to make the leap. Once I told one person I was compelled to tell a few more and it did help to talk about it with different people. It gets easier with time and if you are struggling with the decision to tell someone, I highly recommend you do. Of course make sure this is someone that you trust and know will support you. Having people on 'the inside' of your care will help with every aspect of your journey. That is what this is, a journey…. I hope sharing my experience can help ease others minds that this isn't the end of the world and life is going to keep marching on and driving you crazy just like every other day of your life before you were diagnosed. It's just a little more interesting now." (66)

The above post demonstrates the impact that engaging with social support networks can have on one's emotional well-being; as there seems to be a sense of relief to feeling less alone with the diagnosis.

The findings in this study suggest that the experience of receiving an HIV-positive diagnosis is greatly impacted on by the social support provided to an individual, often following a disclosure of their status. It seems that disclosure is strongly influenced by stigma, and the support that may be received from partners, family and friends to whom one discloses impacts on one's adjustment to the diagnosis. The fears surrounding internalised and anticipated stigma is apparent in the post below, where there is seemingly surprise experienced by the online forum user, when a friend will drink from the same glass as them; a simple act of understanding and acceptance.

> "…. Sometimes I feel optimistic that I will outlive the disease that I can live with this for 20+ years until they find a cure…. There have been changes to my body as well. In all this I had the support of this friend of mine. When I told her I tested positive, the first thing she did was to give me a badly needed hug. She took me to a local beer fest and shared a glass of beer with me. I nearly broke down crying after that." (38)

An HIV-positive diagnosis often brings with it an experience of loneliness possibly never felt by an individual before. Data in this study described the sense of feeling isolated in one's community, as the diagnosis creates an immediate sense of being different due to the expected stigma.

> "I was walking around positive and didn't know it.... As far as I know HIV is not big in the cross dresser community and I feel really isolated and alone. I am also very upset to come to terms that I might have to wear a condom for all oral sex for now on...it has taken me a long time to muster up enough strength to reach out and talk about it." (10)

There is interplay between sexual behaviours, sexual orientation, lifestyle and intimacy in the context of HIV. All of the posts in this study that explained how the virus was contracted were through sexual behaviours, and a number of posts described the influence of their sexual orientation on the experience of being diagnosed HIV-positive. The following post reflects research findings showing greater levels of enacted stigma surrounding certain sexual orientations, and the internalisation of this stigma by the online forum user (Earnshaw et al., 2013).

> ".... I am alone in this foreign country with my entire family, all my friends back in my homeland. I mean, being gay I was always in the high risk demographic but I never had unprotected sex in my life, rather never had much sex at all, so I am still trying to figure out the source of infection. I hope I learn to live with it...." (21)

Research has shown connections between perceived, and experienced, discrimination towards sexual orientation, and greater stress and an increase in risky sexual behaviours (Fields et al., 2013; Frye et al., 2015; Malebranche, Gvetadze, Millett, & Sutton, 2011). Stigma surrounding sexual orientation and HIV, and personal beliefs regarding these may impact on the meaning making of an HIV positive diagnosis, and the battle of placing blame and finding ways to cope, when expected alienation due to one's status becomes a reality.

> “I was struggling with my sexual orientation before I tested positive so taking steps to protect myself was last on my mind. Of course now being gay is the least of my problems, but I certainly wished there wasn't all this stigma and taboo around being gay. I spent the first few months blaming society for what had happened to me. Not entirely justified but it helps me live with my own mistakes. The first year has been a roller coaster ride emotionally…. Times I am convinced that I will die of depression when I refuse to take my meds after getting rejected for the n-th time by some ignorant HIV-cutie….” (38)

Appropriate and reliable social support influences an individual’s ability for positive emotional and psychological growth following an HIV-positive diagnosis (Zeligman et al., 2016). The experience of being diagnosed HIV-positive is a complicated and difficult process that may be assisted by networks of social support and feeling accepted by others, as well as the measures of resilience already existent within an individual (Kelly et al., 2008).

> “…. The next week was constant crying and feeling absolutely horrible, I feel like only other people who were diagnosed with HIV knows that feeling I'm talking about. The day before my appointment I got the call with the confirmed western blot test I cried again…. I cried on the car way down in complete disbelief I was actually on my way to an HIV specialist. Once I went into the place and saw the doctor, she made me feel like I was going to be okay and that I can overcome this! Overall meeting the doctor made me feel so much better…. I would say I do feel depressed and lonely right now, I also can't seem to think good about my looks anymore, I’m a very good looking guy, and I just uhh feel so weird now, I turn down every guy who writes me online, I don't let anyone like me, because I feel Lethal with a poisonous bite…. I have the support of my family and best friends, but I would love to have friends who are also HIV +, for support from someone going through the same thing. I know I'm going to make it through this….” (68)

The process by which one shapes and forms an understanding of an HIV-positive diagnosis, may result in different outcomes for the individual, and often involves perceptions of rejection and anticipated stigma (Kelly et al., 2008). Described in the post above, when the expectations of discrimination and isolation are not experienced, the support received may have a positive impact on one’s mental health and help minimise the psychological responses of depression and hopelessness (Kelly et al., 2008).

From the online forum posts, it seems that the result of a supportive response from disclosure to a family member or friend, may allow for greater acceptance and optimistic thoughts about the future. The support from a partner can be complicated when one partner has transmitted the virus to the other, however, this seems to be influenced by whether there has been betrayal and lies within the relationship or whether the partner was unaware they were infected from previous partners.

> "Not really care who or how or when I get it, not blaming, but if this thing is running more than few years I would like to know since I have a big list of people to call and advise to blood test. I have family and friends and a girlfriend who support me/each other and I'm not scared or alone on facing new life. I'm just big worry of this low CD4 and its opportunistic infection." (32)

The posts above and below describe the complexities of responsibility, blame and the mediating impact that receiving support may have, following disclosure, both when one is aware of the exact behavior through which the virus was contracted, and when it is unknown. These posts demonstrate how responsibility for contracting the virus can be felt across various circumstances.

> "I finally was confirmed positive about a week ago. I was able to tell my husband and the fact I messed with someone outside of the relationship. He is pretty upset but he said he will support me through sickness and health, I could not imagine doing this alone right now. I'm sort of wondering what's going to happen next…" (78)

For individuals where offline support has not been forthcoming or the fear of disclosure is too great, as described in the following post, the online forum community offers a space where one may begin to feel accepted, and have started the process of acknowledging the reality of the diagnosis.

> ".... I guess I just need to vent. There are no support groups where I live, and I can't talk to my friends or family because they do not know about my status. I don't know what to do anymore, and just tired of it all…" (97)

Here, the post reflects how the online forum may be an important space to turn to, when an individual feels as though they have no other support.

> "…. Hardest part for me right now is that I don't really have anyone in my life that I can talk to about this and I'm feeling very alone." (99)

There are certain realities that come into the process of making meaning out of an HIV-positive diagnosis, of which one is the fact of carrying an infectious virus (Kelly et al., 2008). This reality, experienced by the following online forum posts, is understood to impact on to whom one decides to disclose, and creates restrictions and complications for future relationships, and sexual activity (Kelly et al., 2008). Advice and support is sought, on the online forum, regarding the impact of HIV on one's lifestyle and intimacy with current or future partners, and the means by which HIV may be incorporated into one's life. The process of making meaning out of an HIV-positive diagnosis involves the shock and emotions initially experienced, and then exploring changes to lifestyle, making decisions, changing perceptions, reflecting and settling into a new view of one's life (Baumgartner, 2005). It is the beginning of this process that is expressed on the online forum in this study, and support for moving through the process is sought. For some individuals, part of the experience of receiving a diagnosis, may involve focusing on how HIV can be incorporated into one's current life, instead of having to completely change one's life in response to living with HIV.

> "…. I tested positive about 10 days ago and struggling to keep it together…. So many questions, fears, worries…. I'm anxious to get started on meds, and hopefully the night sweats will go away. They're really annoying. But I'm worried about side effects…. And then there's our sex life. Even after 16 years it was still good…now this has just killed it. In my head, sex and HIV are linked and I can't even get an erection. I know it's only been a few weeks, so maybe I can get to a better place…but I want him to be satisfied and I wonder if we can ever have a normal sex live ever again. Another thing for me to worry about." (113)

> “I've been newly diagnosed a month ago. I cannot pinpoint when it happened or when I was more at risk, the only guilty feeling I have now is my lifestyle, because even with playing safe I knew this put me more at risk. One of the things in life I like to do is party and sex. And now I have the feeling that this lifestyle that is part of my happiness if also the thing that is destroying me. She made me feel like I have to abandon all of this. I mean if I have to I will, but it will be difficult at this age. Any guys out there who have the same lifestyle? And how did you adapt after diagnose? I have a summer of holiday/party planned and now I feel I should not enjoy it and take it easy and change my lifestyle completely.” (50)

The realities of an HIV-positive diagnosis, of living with a chronic disease, being infectious, and the expectations of stigma and how one will be treated by society, are expressed in some of the posts (Kelly et al., 2008). There may be added fear when it is unknown how or when the virus was contracted, and the anxiety as a result of not knowing who to trust (in a sense of being alone against the world) is expressed in this post.

> “…. I still don't know how this happened. My whole perception of people has changed. I don't feel I can trust anyone anymore. I have no idea how long I've had it. On top of this now I'm freaking out that through some freak chance I've passed it on to my parents. I want to run away to some desert island where no one will find me and only have my meds (whenever I get put on them) shipped to me.” (28)

Even with social support networks, the online forum may offer a community where one can feel accepted, understood and therefore less alone.

> “…. I've been living with my secret for almost a month now. I've managed to tell one person. I can't tell my parents. It won't kill them but it will kill me knowing their worst fear has come true. I want to run away. Leave a note saying I'm sorry. I'm alive. Don't come looking. All because I don't want to say it. I don't know how to say it. Those three letters to them will change everything. I need help. I need something. I need someone.” (29)

> “…. I just want to talk to someone and tell me its ok that my life isn't over. Because I can't help but feel like it is. I just wish I knew how to tell my family….” (122)

Within the discussions of disclosure, stigma and social support is an underlying emotion of fear that can be deeply present, and felt, in the experience of an HIV-positive diagnosis.

> "…. I feel kind of lost and alone right now, I just need someone to hear my story just in case something happen…. It was really hard the first couple of days and nights and I was thinking about ending my life but I found reason to fight this. I told my parents the first day I found out and they understand everything and accepted me as I am and that is the main reason I didn't do anything stupid then. I'm still afraid...I fear the stigma and how people will react. It's been my biggest fear in life ever to get infected and to die because of this…." (74)

Even though HIV-positive individuals can live normally with the management of medication, feelings of shame, guilt and psychological struggles with disclosure, stigma and acceptance, are often still significant in individuals' experiences.

> "Still getting used to being positive. So far what I hate most is the constant hiding, hiding to do your labs, hiding for doctors visits, lying about the reason for the doctors visits, hiding medical records, asking for confidentiality all the time, walking away from situations where HIV is mentioned, hiding, hiding, hiding. I feel like I'm living a lie…. I'm naturally a happy person, but with this HIV nonsense all that has changed. I have good days but still a lot of bad days, and it's like I have to struggle more these days to remain happy but I believe it's a choice I have to make." (100)

4.6 Theme 5: Thank you – life can carry on

The posts regarding the support, information and advice that is offered on the online forum, suggest that it is a community that takes care of each other. Through sharing on the online forum, individuals are able to feel less afraid, as a sense of belonging to a community is created.

> "I'm still kind of in shock but reading the posts on this forum has helped me a lot…. This seems like a very supportive and helpful community for which I am extremely grateful. Still trying to process everything and this forum is making it a lot easier." (24)

In a study exploring the use of a message board for individuals suffering from Complex Regional Pain Syndrome, members were able to feel a sense of belonging through sharing and engaging with others who had experienced similar struggles and feelings, as well as feel free to express themselves and gain information and support (Rodham et al., 2009). Even with social support from family and friends, it seems the sense of belonging experienced through engaging with other HIV-positive individuals on the online forum, where information, advice, and support are offered, may aid in the process of coming to terms with the diagnosis.

> "…. I fell in to a depressive phase for about a week, but when I found this website and other peoples stories, it gave me a form of relief that I'm not alone…. So just wanted to share my story, hopefully we could motivate each other here. I find this a really good support system besides my parents and siblings." (106)

As the online forum is accessible for reading to anyone in the public domain, some individuals spent time reading through the online forum posts before becoming members and posting themselves. The experiences of shock, and decisions surrounding disclosure, may sometimes need to be processed before an individual feels able to join the online community for support.

> "Honestly just reading through everyone's posts of people who had been where I am now gave me the strength to fight this head on. The day I got the diagnosis I thought my life was over but I now see that it is only just beginning…." (8)

The support offered on the forum allows for the individuals to feel that it is a safe space and may help to shift one's experience of receiving a diagnosis, as the sense of isolation and loneliness felt after being diagnosed is eased through accessing others' stories and sharing one's own. As the online forum is accessible 24 hours a day for those with Internet access, it can function as a space to share intimate feelings and thoughts, and share positive change following the traumatic experience of an HIV-positive diagnosis.

> "Thanks for the kind words guys. I did manage to go to the grocery store today for a few items. I wasn't in there for long and was panicky the whole time, but it was a big step forward for me." (58)

There are emotions of deep gratitude experienced by members who access and interact on public online spaces for support with HIV and AIDS (Bar-Lev, 2008).

> "…. I have been reading many of the posts on here and they have helped me feel less isolated and afraid. For that, I thank everyone tremendously…." (11)
>
> "First I just want to say thank you to all of you who take active part on this board - it is really really helpful to people like me, who get diagnosed and lost. Last month was and is a nightmare for me…. I can't tell how I feel - there is no word. Anyway what doesn't kill you makes you stronger, once more thank you all for a great source of information." (53)

The findings in this study support the research that social support can have a positive impact on the development of "posttraumatic growth" following the traumatic experience of an HIV-positive diagnosis (Zeligman et al., 2016, p. 141). The support offered by the online forum may help to encourage positive psychological changes and new meanings for life, following an HIV-positive diagnosis.

> "Yesterday I was diagnosed positive. Still reeling of course. Have my moments that I'm fine and then a wave of sadness hits me and I cry a little. Luckily, I already had a scheduled appointment with my primary care doctor today. On my way there. This is one of the first places I discovered and I immediately signed up. I am completely overwhelmed and in awe of the incredible support and words that many have already posted. I read through several threads and though they weren't directed at me, I still felt all the love and virtual hugs and support. This is the greatest site right now for me.... Reading all the stories and uplifting words has helped so much in less than 24 hour since my diagnosis. So, mostly I guess this is to introduce myself, and to shout out a huge thank you to many of you who might be strangers now, but whom I soon hope to call friends. Thank you!" (105)
>
> "Two years ago, I found out I was positive. I was scared. I was full of guilt. I was angry with me. With him. With life. I was there, too. In a place of self-hatred, self-loathing, self-destruction. I was there, y'all. Trust me. Then I searched online for an answer. Here you will find some interesting relationships, some may mean more to you than that of family and friends at this time. Here you will feel completely at ease. Here you will feel enraged. Here, you can be. Positive. Loved. Be glad you're here. It saved my life." (18)

The above post describes the support that has been experienced as offered on the online forum and the immense positive growth that is possible following a diagnosis. Further to this, encouragement is offered on the online forum to those less recently diagnosed than others.

> “…. I have grown a lot from where I was and I learnt to take care of myself and think about those around me. I guess you learn many lessons in life and know not to do it again. I wish everyone with recent diagnosis all the best, things will be okay learn to love yourself and take it one step at a time.” (4)

The combination of social support and psychological resilience has an impact on one’s ability to cope with, and adapt to, the stress of receiving an HIV-positive diagnosis and withstand the potential for a negative mood to persist (Treisman et al., 2014). Linked to the emotional experience of accepting an HIV-positive diagnosis, the knowledge about advancements in treatment and positive stories from those living with HIV, may help to ease the process of adapting to the diagnosis. Knowledge therefore may not be able to always protect one from harm or from contracting HIV, but it may serve to positively shape the way in which a diagnosis is experienced and understood.

> “I'm new here and just tested positive last week…. But fortunately what I've read on this forum on how this isn't a death sentence anymore gave me hope. Fortunately for us, in our country both the doctor appointments and the meds are completely free. I have to say reading the forum and your advice as a guest here has been an invaluable resource for us in terms of information and life experience from people who have been living with HIV for a long time.” (83)

> “…. I do know though, that the medications have advanced very far from what most people know about and they are extremely effective…. You may have an adjustment period with the medication where you will have side effects, but with the newer medications these are generally relatively tolerable side effects…. I've found this forum to be incredibly helpful and informative. It's also nice just being able to talk to other positive people and hear their stories.” (57)

Qualities of hardiness and resilience are associated with adapting to living with HIV, namely maintaining meaning and purpose in life, adjust to change, and a sense of agency and belief in being able to control one's life (Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000).

> "…. I have good days but still a lot of bad days, and it's like I have to struggle more these days to remain happy but I believe it's a choice I have to make." (100)

The coping mechanism of "positive reframing" involves directly engaging with the stressor on a cognitive level, and forming an understanding where the HIV-diagnosis is integrated into one's life (Weaver et al., 2004, p. 176). The use of this type of coping strategy positively impacts on an individual's overall well being (Weaver et al., 2004).

> "…. I take full responsibility for my actions or lack of actions that have brought me to where I am now, so there's no point in crying over spilt seed so to speak at this point now is there.... Mentally my diagnosis has quite honestly been a huge wake up call for me and I now do my best to squeeze as much life out of every day as I possibly can…. Being positive…will not define me, it's merely another fact in the long list of facts about me…. I just don't have time to let it run my life because I have other stuff to do, like work and actually enjoy life, let myself fall in love again." (80)

Further to the positive and motivated experiences expressed, some of the posts described feeling a sense of empowerment and a responsibility to help others with the experience of being diagnosed with HIV. In order to fight against stigma, the development of social interventions that mobilise HIV-positive individuals to fight for, and own their identities and rights, to become social activists, and increase the access to support groups, are important in order to empower people living with HIV and AIDS (Deacon, 2005).

> "…. I want to become an HIV activist and share my story along with helping others coping with the diagnosis. I would love to talk to young people like myself…to tell them, it can happen to you! I never thought this would happen to me, but it did, and if I can get it through to young people who are still negative and make them realize hey I can protect myself from getting this horrible disease and dealing with all the things that come along with it, then do it...I honestly feel in my soul that this Is what I need to do and somehow help with the prevention of HIV in young people around the world. I just don't know how to go about it. Any advice from people looking to get into the same thing?" (75)

> "…. I know I'm going to make it through this, and turn something positive out of this negative situation in my life. Whether that's becoming a motivational speaker, HIV activist or something along those lines I'll find my place, but I refuse to let this virus control my life. Know one ever knows the true value of life until your life has been threatened to be taken away. I now know the true value of life and I will become wiser stronger and a better person then I once was…I have HIV, and I'm going to take this chin up never knees in the dirt." (68)

Through the use of adaptive coping strategies, the traumatic experience of receiving an HIV-positive diagnosis can be experienced as an opportunity for a new, and improved, lens on one's life.

4.7 Conclusion

The findings discussed in this chapter suggest that the experience of an HIV-positive diagnosis is a complex process of shock, disbelief and a multitude of emotions including blame and self-blame. Due to the shock, it may take some time for the reality of the diagnosis to be realised. However, a need for information and answers may then follow as an individual attempts to make meaning from the diagnosis. The online forum is a platform where advice and support are sought, and the difficulties with decisions regarding disclosure are expressed, as well as it being the place where first disclosures may be expressed, due to its sense of a safe space. Part of the experience of a diagnosis is its impact on an individual's mental health, specifically feelings of hopelessness and a depressive mood and behaviours, and this is further influenced by the various experiences, both external and internalised, of stigma. The findings from the study indicate that social support can act as a buffer for an increased negative experience of an HIV-positive diagnosis. The experience of receiving an HIV-positive diagnosis can be mitigated through the presence of social support, both from family and friends, and the support network of others living with HIV, on the online forum. Coping strategies and resilience impact on how an individual adapts to the life change of becoming HIV-positive, and, as the final theme indicates, there is the possibility for recently diagnosed HIV-positive individuals to reframe their experience in a positive way, to benefit their quality of life moving forward.

Chapter 5: Conclusion

5.1 Introduction

This research aimed to explore the experiences of receiving an HIV-positive diagnosis, and the support sought through analysing posts shared on an online forum. A review of the literature, description of the methodology and research design, and a discussion of the findings were presented in previous chapters. This final chapter reflects on the main findings and the research process, and describes the limitations and suggestions for future research.

5.2 Reflection on the research process and findings

The focus of this research is on the experience of receiving a diagnosis of HIV, and the expression of this experience in the space of an online forum. As the focus is on experiences, IPA formed the framework from which the data was explored and interpreted. Aspects of the methodological process in this study differ from the common methods used in IPA research. Data was not collected by semi-structured interviews and the sample consisted of a large sample of relatively short excerpts. However, although some of the methods were different from what is most common for IPA research, the analysis maintained a focus on understanding the meaning an individual makes of an experience, within the specific context of an online forum. Through analysing the initial posts made by individuals, there are a number of reasons that have brought individuals to speak about their experiences on the online forum, as opposed to in other contexts. This therefore situates all of the posts in a specific context, and allowed for interpretation of the experience of a larger number of individuals, following a particular event, across wide social and cultural contexts.

The interpretations in this study were made from the descriptions of experiences not directly provided to the researcher in a face-to-face interaction. It is of interest to note that as the posts are written to a somewhat unknown audience by the individuals, it is likely that the emotions and thoughts, in reacting to the experience of an HIV-positive diagnosis, expressed on the online forum, may be highly honest and authentic. Therefore the data for this study consisted of excerpts that were not probed by any questions, and not tweaked or changed for a specific audience, but rather individuals making meaning of an experience, in an open and exposed manner. The researcher in this study therefore attempted to make meaning of how individuals understand an HIV-positive diagnosis, via the unknown third party of the other online forum members.

Reflecting on the findings from the study, it seems that the online forum is utilised as a means of accessing information and advice, possibly because, due to the shock commonly experienced following a diagnosis, one may not be able to think clearly or listen to any information provided by health care professionals. The chronic nature of the virus seems to be acknowledged in the experiences, as there is an urgency to take control of the virus as soon as possible. The online forum allows for an often private and lonely experience of receiving an HIV-positive diagnosis to be made open and for individuals to feel as though there is someone to talk to and feel supported. It is of interest that with fears of confidentiality and disclosure, individuals are able to express themselves and voice their feelings to an unknown space and unknown people. Therefore, as the world becomes less connected physically, and more connected by technology, individuals can feel more support by words and replies on a computer screen than from face-to-face interactions with family and friends.

It is seemingly the non-judgemental space of the online forum that can help individuals with feelings of self-blame and guilt, through sharing stories and hearing from others how they are coping and possibly how they have been able to forgive. Unlike many other chronic illnesses, HIV is transmitted by specific means, and often through a single act of sexual behaviour. During the analysis in this research, the feelings of blame and guilt seemed to be felt with the same intensity as can be experienced in grief. The individual's experiences are felt with a desperate longing to go back in time and reverse the act that transmitted the virus, as with grief there is often a longing to go back in time to behave differently to the person who has passed away. Some posts described the struggle to understand and make sense of betrayal by partners. This sense of betrayal complicates the experience, as one may feel love for, and anger towards, the person at the same time, as the betrayal may be experienced in their bodies forever, through the virus.

A rollercoaster of emotions was used to describe the process of adjusting to an HIV-positive diagnosis. Individuals post on the online forum at different stages of the rollercoaster, and the emotions experienced include anger, denial, shame, hopelessness and depression. Of particular significance are the experiences of hopelessness and depression, as often the consequence of these feelings is suicidal ideation with the sense that the experience of having to disclose one's status and the impact it will have on others, may be too much to handle. Widely documented in the literature is the role of stigma towards HIV and the impact that forms of discrimination have on the support offered, and experienced by, individuals living with HIV, and the decisions surrounding disclosure. In the findings, some posts, particularly in relation to sexual orientation, described fear of stigma. It is of interest to note, however, that although it can be understood by the researcher that concerns and worries around disclosure are intrinsically linked to internalised or anticipated stigma; this was not always openly expressed in the online posts.

The availability and accessibility of the online forum allows for individuals to access a social support network at any time, if there is Internet access. In South Africa, as with other developing countries, within the divide between rural and urban populations there exists a difference of access to telecommunications (Dalvit et al., 2014). The presence and use of smart phones within rural South Africa has increased over the years, however, the cost of data means that using one's phone to access the Internet remains unaffordable for much of the South African population (Dalvit et al., 2014). The lack of sufficient telecommunications infrastructure in South Africa has implications for access to the type of online forum in this study. Therefore, it can be determined that there are many HIV-positive individuals, who may feel isolated and alone, and would benefit from the support shared on the online forum, if they could access the Internet or afford to buy data to search the Internet on their phones. The active and passive role of the online forum mediates the experience of an HIV-positive diagnosis for the individuals who read through the forum, and then posted in gratitude, or those who share more frequently with other members. The role of social support, both offline and online, for HIV-positive individuals, is important as it can assist in alleviating a lot of the negative experiences and moods, through helping individuals feel less alone and increase a sense of coping.

The five themes discussed in the findings for this study demonstrate that an HIV-positive diagnosis is seemingly followed by confusion, feelings of shock, denial, anger, guilt, blame and hopelessness, and a need for reassurance. Questions and fears around disclosure are common and influenced by perceived and experienced support. At times the support experienced from the safe and sharing space of the online forum was described as assisting in the experience of resilience and a positive attitude for moving forward with one’s life following a diagnosis.

5.3 Limitations of the study

As this study focused on the initial posts in the threads on the online forum, a retrospective account of the replies, and further comments on each of the posts, were not considered. This did, however, allow for the first description of the experience of an HIV diagnosis to be focused on, and explored. As previously acknowledged, the nature of the study did not allow for further probing in order to obtain a greater depth of the experiences, due to the data being obtained from an online forum rather than from semi-structured interviews. This limitation, however, allowed for a wider sample of experiences to be analysed, as well as the possibility of honest, unbiased and unmediated expressions of experiences due to their being shared on the open space of the online forum.

5.4 Future research suggestions

Internet-based research is more widely acknowledged and therefore further studies into the use of online forums on a longer term scale, for people living with HIV, could add to the literature, and possibly help to encourage access to more support and strengthen the other online resources by which individuals can be helped. Specifically within South Africa, future research could also be used to strengthen the policies for greater infrastructure to be developed, to increase access to the Internet for thousands of newly diagnosed HIV-positive individuals, who could benefit from the sharing of experiences, information and support on an online forum.

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