An ecological analysis of the stories of fourteen HIV infected and affected individuals.

By

Xithembiso Khosa

Supervised by Kerry Frizelle

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DECLARATION

I declare, that this dissertation is my own work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Masters in social sciences (Clinical psychology) in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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ABSTRACT

This interpretive study adopted the ecological framework of Bronfenbrenner with the aim of understanding the health experiences of fourteen HIV infected and affected individuals. This model looks at the experiences of an individual in a holistic manner by taking into account their subjective experiences as well as the wider social environment that influences and shapes their experiences of health and illness. Fourteen HIV infected and affected individuals' stories were used from the book titled *28 stories of AIDS in Africa* by Stephanie Nolen. Thematic analysis was used to analyse the data. The study revealed that adopting an ecological framework was a useful way to examine and understand health and illness among HIV infected/affected individuals. The findings of this study suggested that some of the intrapersonal factors which were evident in shaping the health or illness of the HIV infected and affected participants included factors such as knowledge, denial, acceptance, a range of emotional responses, and resilience towards being HIV positive. Furthermore, it was evident from the study that some participants were ostracized, rejected or abandoned by their families and colleagues as a result of disclosing their HIV diagnosis. Other participants, however, experienced positive consequences, which facilitated acceptance and social support thus enhancing their physical and psychological well being. Family support also influenced the wellbeing of some HIV infected individuals. The analysis suggests that among the infected and affected HIV participants, some of the community factors that influenced their experiences of health and illness included poverty, stigma, gender inequality, and difficulty negotiating safe sex with partners. It was also found (in line with the ecological framework) that the different levels of analysis (intrapersonal, interpersonal, institutional, community and policy factors) were interrelated or interdependent thus affecting the health and wellbeing of the participants in complex and intricate ways.

CONTENTS

CHAPTER ONE: INTRODUCTION

HIV/AIDS is a topic that has been discussed and researched to a great extent due to its impact on humanity especially in developing continents such as Africa (Bezuidenhoudt, Elago, Kalenga, Klazen, Nghipondoka, & Ashton, 2004). Those living with HIV/AIDS are referred to as 'infected', while the personal caregivers and family members are referred to as 'affected' (Bezuidenhoudt et al., 2004). Human immune deficiency virus (HIV) is an infection that destroys the immune system of the individual who is infected. AIDS is defined as "a collection of many conditions that manifest in the body because the HIV virus has weakened the body's immune system that can no longer fight the pathogen that has invaded the body" (Van Dyk, 2001, p4). According to the World Health Organization (WHO, 2005) , HIV/AIDS infected individuals face a variety of stressors that are likely to be experienced by other patients with chronic illness, such as long-term worry, weakened physical well-being, physical and financial dependence and ultimate death. An estimated "total of 2.7 million people acquired HIV infection in 2010, down from 3.1 million in 2001, contributing to the total number of 34 million people living with HIV in 2010" (UNAIDS, 2011, P.2). In addition, it has been highlighted that: more and more people living with HIV were able to access counseling as well as treatment (UNAIDS, 2011). It has been stated that there has been decline in HIV related deaths especially in the low and middle income countries due to large supply of antiretroviral therapy or treatment(ibid).Similarly, the decline among newly infected HIV individuals has been evident worldwide, though in poor resourced countries HIV epidemic continues to expand. "In Africa, an estimated 1.9 million people became infected in 2010" (UNAIDS, 2011, P.12).

According to the UNAIDS (2010, p. 1) there has been an estimation of "22.5 million people living with HIV by the end of 2009 in sub-Saharan Africa, 1.8 million new infections within this region, and 1.3 million AIDS related deaths by the end of 2009", whereas, in the Middle East and North Africa "460 000 people are living with HIV, 75 000 new infections and 24 000 AIDS related deaths" (UNAIDS, 2010, p. 1).

However, in some African continents there has been a decline due to treatment and prevention campaigns. The decline in HIV prevalence evident in countries such as Burkina Faso, Botswana, Democratic Republic of the Congo, Ethiopia, Ghana, Kenya, Malawi, Nigeria, Namibia, Togo, United Republic of Tanzania and Zimbabwe. Four of these countries (Botswana, Malawi, United Republic of Tanzania and Zimbabwe) also had statistically significant declines in the general population based on the results from population-based surveys more specifically among women who originates in countries such as in Botswana, Malawi (UNAIDS, 2011).

The HIV/AIDS has had a devastating impact in sub-Saharan Africa where infections rates are high and medical resources are limited (Anderson & Doyal, 2004). It has been argued that across the African continent HIV continues to progress, the most severely affected regions being the southern and eastern parts of Africa, causing a devastating impact on the continent because it leads to "declined standards of living, reduced capacities for personal and social achievement, an increasingly uncertain future (with important consequences for what can be achieved today) and a diminished capacity to maintain what has been secured over past decades in terms of social and economic development" (Commission on HIV/AIDS and Governance in Africa, 2006, p. 5). Moreover, in countries such as Botswana, Lesotho, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe there is an estimated an increase in number of people infected (Commission on HIV/AIDS and Governance in Africa, 2006). It has been pointed out that HIV/AIDS related deaths can disrupt income of families as well as cause a rapid disruption in the quality of life of family members due to poverty (ibid). In addition, the Commission of HIV/AIDS governance report (2003) argued that the productive sector is also affected in a negative way due to the pandemic within the continent because it broadens the shortage of skills or lack of resources thus leading to more poverty and thus impacting on the mental health of individuals who are living with HIV/AIDS.

Extensive research about HIV/AIDS issues tends to focus more on the intrapersonal factors of the individual while rejecting the environmental factors that shape health and illness. It is clear that most research on HIV/AIDS tends to look at separate aspects of HIV/AIDS like stigma, denial, acceptance, treatment and social support, but few studies have explored it from an integrated perspective (Chovwen & Ita 2006; Duncan, Harrison & Toldson, 2005; Nam, Fielding, Avalos, Dickinson, Gaolathe, & Geissler, 2008).

Therefore my study has adopted an ecological model to understand the health of people with HIV/AIDS, taking into account the social context of an individual and focusing on multiple levels of analysis rather than on only the intrapersonal level. The ecological model places people in social systems and seeks to look at individuals in a holistic manner within the social contexts in which they are embedded to understand their health and behaviour (McLeroy, et al., 1988). This study explores the experiences of fourteen HIV infected and affected individuals.

The aim of the study, therefore, was to answer the following questions:

- What intrapersonal factors are common in the participants' stories?

- What interpersonal factors are prevalent in the participants' stories?
- What organizational factors are prevalent in the participants' stories?
- What community factors are prevalent in the participants' stories?
- What policy factors are prevalent in the participants' stories?
- How do the different levels within the ecological model work interdependently to influence the participants' experiences?

It is hoped that the findings of the study will, firstly, influence future studies to consider the influence of the social context that individuals are embedded in to understand the experiences of HIV/AIDS infected and affected individuals. Secondly, I hope that my findings will also contribute to the design of HIV/AIDS interventions that take the social environment of individuals into consideration.

This dissertation consists of five chapters of which Chapter One has provided an overview of HIV/AIDS statistics globally and within Africa, as well as briefly highlighting the social, economic and emotional impact of HIV/AIDS across Africa amongst HIV infected/ affected individuals. Chapter Two consists of a literature review and theoretical framework, which includes a review of literature on health psychology and mainstream approaches to health. It also covers a review of research on HIV that is framed by the ecological model, and emphasizes the significance of adopting an ecological model for my study. In Chapter Three I describe my research methodology discuss my research design, sampling technique and sampling size, data analysis as well as ethical considerations. Chapter Four consists of an analysis and discussion of my findings in relation to the theory and research discussed in the literature review. Lastly, in Chapter Five I present my conclusions where I summarise my main findings and make some concluding comments about my findings in relation to the wider theoretical framework. In the conclusion, I also discuss the contributions as well as the limitations of my study.

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Health psychology and its limitations

According to WHO (2005, p. 176), health has been defined as "a state of complete physical, mental and social well-being". Boruchovitch and Mednick (2002) argue, however, that the concept of health tends to be biomedically oriented in nature. They contend that health is often defined "only in terms of the lack of disease, symptoms, signs or problems", and that the biomedical approach places too much emphasis on specific diseases and how they affect parts of the body, while ignoring the human being as a whole and in particular, the individual's experience of ill-health (Boruchovitch & Mednick, 2002, p.176). On the other hand, a more recent framework for understanding health and illness is through the bio-psychosocial model, which incorporates the physical, psychological and social processes (Murray, Nelson, Poland, Maticka-Tyndale and Ferris, 2004). However, these authors state that this approach has restricted its research to a number of socio cognitive models and their "relationships with health related behaviours" (p. 327). In this way the focus of this approach has primarily been intrapersonal and has largely overlooked the role of social processes in relation to experiences of health.

It is important to note the use of the two similar concepts in the above paragraph: disease and illness. 'Disease' is a biomedical concept, and Swartz (1998) refers to the work of Kleinman(1977) who makes a distinction between 'disease' and 'illness', defining "disease as the malfunctioning of the body, and illness as the lived experiences of suffering" (Swartz, 1998, p. 14). Kleinman argues that "it is not enough to understand the physical disease of any person, though this may be universal. What is equally important is the person's experience of illness and distress, as it is this experience which will determine how the person behaves, the treatment they seek and their reaction to treatment" (Swartz, 1998, p. 14). Swartz (1998, p. 14) concludes that although there are different definitions of disease and illness, "disease can be seen to stand for the doctor's perspective on disorder and illness". Swartz (1998, p. 15) highlights the importance of the 'patient's perspective' and therefore the importance of exploring the patient's "illness experiences". In recognition of the importance of focusing on experience, the rest of this review will make use of the term 'illnesses"

According to Murray et al. (2004), an extensive amount of literature in the sub-discipline of health psychology focuses on individual or micro social issues. For instance, how socio cognitive models can be used to understand why people experience ill health, and help people adjust to and cope with illness. Furthermore, health psychology has presented with a number of limitations which tend to disadvantage people who are experiencing health problems because it is individually based and tends to ignore not only the personal experiences and meaning of illness, but also the social aspect of health and illness (Murray et al., 2004).

Furthermore, health psychology interventions are biomedically orientated and are based on the assumption that if people's values, attitudes or beliefs (at the intrapersonal level) are changed then we can accomplish good health in individuals (Murray et al., 2004). These interventions, however, ignore the environment in which an individual is embedded, since contextual factors are not incorporated in health promotion plans to fight diseases or illness. Moreover, while health psychology as a discipline recognises that social class is associated with certain health-related behaviours, it tends to over emphasise this aspect and thus creates a barrier in exploring the broader social experience of individuals (Murray et al., 2004).

To understand health and illness it is important to recognise that socio political processes play a major role, contend Murray et al. (2004) who maintain that "power is central to our understanding of health" (Murray et al., 2002, p. 326). Similarly, Freund and McGuire (cited in Murray et al., 2004) argue that power shapes health policy and that the views of people in power inform what comes to be regarded as wellbeing, fitness and healing in individuals, disregarding the individual experiences and social development of individuals; for example, the influence of how individuals experience health and illness (Murray et al., 2004).

2.2 A call for a community health psychology

Based on the limitations presented above, Murray et al. (2004) maintain that it is important to consider community health psychology which examines both the individual and their social processes when trying to understand how their health is shaped. Community health psychology is defined as a sub-discipline which involves the interactions an individual is associated with society. Murray et al. (2004) suggest that community health psychology is a useful approach to understanding experiences of health and illness because it views people within social environments and therefore acknowledges and focuses on the important relationships between individuals and communities or environments (Murray et al., 2004).

The relevance of the discussion so far is that it highlights that many problems in health may be the outcome of contextual factors rather than being the outcome of intrapersonal qualities (Murray et al., 2004). In this way community health psychology acknowledges that people are located in their environments. An important theoretical framework that is useful to apply in understanding the relationship between the individual and their environment is the ecological framework.

2.3 An ecological approach to understanding health and illness

McLeroy, Bibeau, Steckler and Glanz (1988) maintain that over the years there has been a need within societies to prevent risky health behaviours and to promote healthy ones, since societies are faced with chronic diseases as well as high rates of deaths; hence health promotion interventions came into place. Furthermore, they point out that though health promotion strategies were aimed at preventing risky health related behaviours as well as promoting healthy behaviours, these strategies were criticized because they tended to "promote a victim blaming ideology by neglecting the importance of societal influences on health and disease" (McLeroy et al., 1988, p.351). Health promotion strategies have been expanded and have been extensively applied in both the private as well as public segments to promote health, for instance campaigns to control cholesterol. The goals and strategies are often limited because they mainly target individual behaviour to alter risky health related behaviours as well as to sustain health while ignoring possible contextual factors that can influence the health of an individual (McLeroy et al., 1988). Therefore some of the limitations in health promotion are that it tends to focus specifically on the health behaviour of the individual while ignoring the influence that society contributes to risky health behaviours among individuals (McLeroy et al., 1988). The ecological model serves to deal with the limitations in health promotion presented above because it takes into consideration contextual factors to understand and modify risky health related behaviours. Hence, it is argued that the ecological approach is a useful perspective when designing effective health promotion programmes that take into consideration the way societies influence health; furthermore, it also targets the contextual factors when assisting in modifying maladaptive health behaviours.

The ecological perspective is informed by the work of Bronfenbrenner [1988] (cited in McLelroy et al. 1988). . McLelroy et al. (1988, p. 351) define the ecological model as "a model which focuses its attention on both individual and socio environmental factors as targets for health promotion strategies and its interventions are directed at changing interpersonal, organizational, and community factors that support and maintain unhealthy behaviours". Furthermore, McLeroy et al. (1988) argue that this model holds the assumption that transformation of the environment as well as support from the population can lead to effective changes in individual health and behaviour. In this way it acknowledges that the individual person is not responsible for their health, but rather that the individual is located in a wider social environment and that the relationship between the individual and their environment influences whether a person experiences health and/or illness. Similarly, Weeks et al. (2010, p. 298) argue that the ecological model "posits that interactive change processes across social levels facilitate or constrain individual and dyadic (partner) or group (network, community) actions and opportunities".

According to McLeroy et al. (1988) Bronfenbrenner's model emphasises the interrelationships between the environment and the individual's quality of life. Bronfenbrenner divided the environment into four levels of analysis by which one could explore its influence on the individual. He referred to these levels as the microsystem, mesosystem, exosystem and macrosystem levels of influence.

According to the ecological model presented by Bronfenbrenner, the microsystem refers to the direct influence an individual can encounter in certain contexts or environments such as associations with family, schools, work networks etc. (McLeroy al., 1988). The mesosystem (the second level of influence) refers to the relationships with the environment in which an individual is embedded (McLeroy et al., 1998) for instance, the interrelations between the church, work, schools, etc. The third level of influence according to Bronfenbrenner's ecological model consists of the exosystem which, as pointed out by McLeroy et al. (1988), includes the aspects that influence an individual who is embedded in larger social system for example, the impact of public hospitals services on an individual's health. The fourth level of influence is the macrosystem and this refers to ideas, viewpoints and the principles that shape an individual within a society or environment (McLeroy et al., 1998) that influence the other levels; for instance, the impact of stigma and discrimination on HIV infected individuals can influence whether one either lives positively or negatively, or how cultural norms and beliefs can influence whether one engages in safer sex practices or not. The example demonstrates how the culture to which a person belongs influences and shapes his/her way of living or health.

Bronfenbrenner's model implies that there is a joint interaction between the individual and their environment and how these levels influence each other (McLeroy et al., 1998). Furthermore, since each level is aimed at changing the behaviour of an individual, these levels are also likely to alter as individuals change. The ecological model can be used as a guideline to develop effective interventions that will view how behaviour is shaped by the contextual factors from which an individual originates (McLeroy et al., 1998).

Bronfrenbrenner's ecological model is borrowed and expanded on by McLeroy et al. (1988) who divide the environment into five levels of analysis. According to McLeroy et al. (1988), these levels of analysis include the interpersonal, intrapersonal, institutional, community and public policy levels. Furthermore, they suggest that several levels from the analysis can act as a guideline to help clarify the basis of maladaptive health behaviours and these levels could also help determine possible strategies to alter health related behaviour. The intrapersonal level of the model includes qualities in which an individual can posses such as of the individual such as knowledge, self concept, behaviour, attitude, etc (ibid). In this way, McLeroy et al. (1988) acknowledge that the individual with their intrapersonal qualities (including attitudes, beliefs, knowledge) exists, but go on to argue that every individual is located in a wider environment. They acknowledge that intrapersonal qualities do have a role to play and can contribute to how the individual deals with experiences such as being HIV positive. So for example, if a person has a strong sense of self-efficacy they might accept their HIV positive status more easily than someone who has a poor sense of self-efficacy. It is important to note, however, that the development of these intrapersonal qualities cannot be separated from the wider social environment. There is a dynamic relationship between the intrapersonal and the environment. So if a person has a poor sense of self-efficacy this may be because they are located in a wider environment of poverty and or discrimination, rather than simply a weakness of the individual themselves.

The second level of analysis refers to interpersonal process which McLeroy et al. (1988) argue include associations with close individuals in which an individual is embedded such as family, friends or neighbours. These relationships are considered to be important because they provide important social support that plays a significant role in shaping an individual within the defined environment (McLeroy et al., 1998). For example, social support from friends can enhance the health of an HIV positive individual. On the other hand, a lack of support from family or friends due to an HIV diagnosis can also have a negative impact on an individual's functioning, hence exacerbating the person's poor health condition and even leading to poor mental health. Although interpersonal factors play a significant role, health interventions that focus on interpersonal processes "have typically focused on changing individuals through social influences, rather than on changing the social norms or social groups to which individuals belong" (McLeroy et al., 1988, p. 357). It has been suggested that most programmes that include social influence, in health promotion tend to disregard the structure and function of social relationships. That is, these programmes tend to focus on social influence rather than the source of the influence or the social groups to which individuals belong. Mc Leroy et al. (1988) argue that from an ecological perspective, interventions should be designed to alter the environment of present social relationships which an individual have been embedded which impact on health related behaviours. Mc Leroy et al. (1998) argue further that while the aim of these strategies is to bring about changes in individuals, the main goal will be to work on the societal rules that might have on the individual to change behaviours as to promote their physical and emotional wellbeing. So for example, an HIV positive individual's family may influence how they respond to their diagnosis. Interventions could, therefore, be directed at the family as a source of influence. Family support groups could be developed as an intervention.

The third level of analysis, as pointed, by McLeroy et al. (1988) includes institutional and organizational factors which are defined as rules that direct the social interactions and behaviours of groups of individuals. For example, it has been found that organizations such as schools and work settings have a significant impact on the health behaviours of an individual. Moreover, McLeroy et al (1988) argue that organizations have the power to influence and support people within the organization through their health concerns. For instance, in work settings those employees who are HIV positive and who get support through employee assistance programmes will experience better health than those who don't.

According to McLeroy et al. (1988), organizations can play a significant role in influencing good health, since people in societies spend extensive amounts of time within these organizations. Furthermore, organizations can act as good facilitates in health promotion to support behaviour change among individuals; for example, incentives can be awarded to regulate change in behaviours as well as "changes in rules and regulations" within the organization can maintain or sustain behaviour changes (p. 360). McLeroy et al. (1988) maintain that organizations can be a significant platform to contrast or alter maladaptive behaviours in an individual.

The fourth level of analysis is the level of the community and refers to "relationships among organisations, institutions and informal networks within defined boundaries" (McLeroy et al., 1988, p. 355). The authors point out that community can have three different meanings. Firstly, community refers to "mediating structures or face-to-face primary groups to which individuals belong" (McLeroy et al., 1988, p. 363). This meaning therefore includes families, peer networks and neighbourhoods. Secondly, "community can be thought of as the relationship among organisations and groups within a defined area" (McLeroy et al., 1988, p. 363); for example, relationships between government health providers and schools in a particular political or geographical area. Thirdly, "community is defined in geographical and political terms" (McLeroy et al., 1998, p. 363). The authors refer to "Power structures" (p. 364) that influence the allocation of resources including funding and materials. This meaning of community highlights that, "health promotion issues, may have political and economic ramifications" (p. 364). McLeroy et al. (1998) point out that those groups that experience the most ill-health are likely to be those who have least access to power structures in a community. For example, people with HIV/AIDS are discriminated against, have little control over how their community operates, and limited access to community political and power structures. Furthermore, they are isolated socially and politically, causing interventions designed to address some of the health concerns to fail. Furthermore, people with HIV/AIDS can become isolated from political processes and power structure because of the way this disease is stigmatised, and because the nature of the illness may mean that they do not have the energy or resources to participate.

The last level of analysis in the ecological model is public policy. McLeroy (et al., 1988, p. 365) argue that "one of the defining characteristics of public health is the use of regulatory policies, procedures and laws to protect the health of the community". They maintain that policies can have a positive impact in addressing health concerns in populations; for instance, policies that state that human beings should not be denied services can facilitate and improve the health of a population and enable access to care that will improve their health conditions. They also highlight the significant association between the role of policy and a community because a community can act as mediators or contributors in policy development processes to achieve change in health (McLeroy et al., 1988).

2.4 The implications of an ecological approach

The overall focus of the ecological model is to take in consideration the environmental causes of behaviour and to discover the solutions that deal with environmental causes (McLeroy et al., 1988). The most important aspect of the ecological perspective, however, is that it is critical of traditional approaches that place too much emphasis on "the role of behaviour in determining health" (McLeroy et al., 1988, p. 368). In this way the ecological model moves away from blaming individuals for their behaviour and recognising the role of environmental factors on health related behaviour. Nelson and Prilleltensky (2005) argue that the ecological model is critical of mainstream psychological models that have placed too much emphasis on individual or intrapersonal characteristics while discarding the influence of the larger social environment in which an individual is embedded . They go on to argue that from the ecological perspective one needs to understand the unjust factors that society can influence individuals of which it can hinder the wellbeing of individuals.

Nelson and Prilleltensky (2005) discuss four principles of the ecological perspective that are important to understand. These principles include interdependence, cycling of resources, adaptation and succession.

The principle of interdependence suggests that within the ecological model, different levels are interrelated to each other and as result any alterations done on one level will have an impact on all the other levels. (Nelson & Prilleltensky, 2005).

The second principle is that of cycling of resources. This principle suggests that resource distribution and allocation should not only be limited to one level within the ecological model since different levels are interdependent with each other. For instance, resources should not only be restricted to psychiatric hospitals or hospitals for discharged patients but rather, they should also be reallocated in communities and families to enhance or provide support for the health of sick individuals within the systems. "The cycling of resources principle also draws attention to potential untapped resources in the systems" (Nelson & Prilleltensky, 2005, p. 72). For instance, an HIV in-patient individual should not only be provided resources to support his/her wellbeing within the hospital setting but also sufficient resources should be distributed following discharge as a way to enhance their health. Furthermore, the "social network, non professional community helpers or volunteers and self help organisations (both for mental health consumers and family members)" can facilitate good health for an individual (Nelson & Prilleltensky, 2005, p. 72). This principle emphasizes the value of community as the most significant resource to enhance the health of people who are ill, as well as of their families.

The third principle, the principle of adaptation suggests that "individuals and systems must cope and adapt to changing conditions in an eco-system" (Nelson & Prilleltensky, 2005, p. 72). It has been pointed out that communities need to adapt to people with illness or health conditions such as HIV, as well as cope with challenges to run support programmes. On the other hand, people with dealing with health issues such as HIV/AIDS have to challenge the stigma which society attaches to such diseases. Further, Nelson and Prilleltensky (2005) argue that if sufficient support from all the levels of the ecological model is provided among individuals experiencing health conditions, wellbeing as well as improved health is achieved.

The fourth principle of succession argues that sufficient time in preparing to tackle health problems such as HIV /AIDS among people is significant . Further it has been highlighted that "succession involves a long-term perspective and draws attention to the historical context of the problem and the need for planning for a preferred future" (Nelson & Prilleltensky, 2005, p. 71).

Nelson and Prilleltensky (2005) argue that the ecological model deals with the significance of holism. Further, this model takes into consideration the contextual factors in which an individual is embedded, and that influence their health (Nelson & Prilleltensky, 2005). The ecological model stresses the strong association between the environment, individual, family, and community to address health related concerns and recognises that any changes within an individual concurrently influence the individual's community, family and environment (Connos & Maidman, 2001, cited in Nelson & Prilleltensky, 2005).

McLeroy et al. (1988) maintain that it is important to see that although the ecological model discusses the importance of environmental interventions to bring about behaviour change, many programmes will not have the resources or capacity to intervene at all levels. Nelson and Prilleltensky (2005) concur, asserting that although those working in the area of health may recognise the need to work at all levels, most interventions have intrapersonal aspect of individuals while neglecting the environmental structures and interventions that form social world of a human being.

Another issue that Nelson and Prilleltensky (2005, p. 78) raise is the issue of power. They maintain that the ecological model does not adequately "take into account or highlight power difference within eco-systems". They argue that it is therefore important to think about the issue of power because it is linked to two other important concepts that are related to the 'ecological model, that is, oppression and well-being which is defined as a state of reaching mental, physical and spiritual satisfaction.

2.5 Framing the review of the literature on HIV/AIDS

The ecological model of McLeroy et al. (1998) described above will be used to structure the rest of the literature review. It is suggested that the model provides a useful way of reviewing the literature to examine the 'level/s of influence' at which research on HIV/AIDS tends to focus. From a preliminary review it is clear that most research on HIV/AIDS tends to investigate separate aspects of HIV/AIDS like stigma, treatment and social support rather than studying the issue from an integrated perspective. In other words, it does not explore the way in which all the different 'levels of influence' come together to impact on the way in which individuals experience their illness. It is argued that the ecological framework is a useful theoretical framework that can also be used to inform the research of people's experiences of HIV/AIDS.

2.6 Intrapersonal factors

McLeroy et al. (1988) argue that the intrapersonal level includes features that occur within the individual's self or mind such as attitudes and behaviour. These factors determine how one will react to certain issues such as health concerns. The following intrapersonal factors are reflected in the literature on HIV/AIDS.

2.6.1 Knowledge

Niccalai, Farley, Ayoub, Magnus and Kissinger (2002) argue that HIV infected individuals' knowledge concerning their sexual partner's HIV status is very important in influencing condom use to avoid HIV transmission to the non-infected partner. Therefore an intrapersonal factor like knowledge plays a significant role in shaping an individual's health. Niccalai et al. (2002) assessed the knowledge of HIV infected individuals about their sex partner's status and the influence on condom use. It was hypothesised that HIV infected individuals who are sexually active are likely to spread the disease due to lack of knowledge regarding their sexual partner's status. The sample consisted of unmarried African American participants who were all above the age of 30 years. The results suggested that "75% of HIV infected people were likely to make an assumption that their sexual partners were HIV positive if it was an occasional partner, whereas, 28% assumed that their sexual partners were infected when they were in committed relationships" (Niccalai et al., 2000, p. 186). In addition, 46% of the participants were precise in identifying their partner's status, whereas, 54% of the sample lacked knowledge regarding their partner's status which had an influence on the decision of whether to use a condom or not. Basically the study suggests that most people who are HIV positive have poor knowledge of their partner's status, which hinders them from using condoms and thus increasing the progression of the HIV virus. Further, the HIV positive individuals were likely to make the assumption that their sex partners were negative only if they were in committed relationships and were likely to avoid using a condom. However, participants who were in casual relationships were likely to use a condom because they assumed that their sex partners might be HIV positive. The results indicated that "the individuals in committed partnerships were less likely to accurately know their partner's status compared to those in casual partnerships; the closer the relationship the poorer the knowledge of partner's true infection status" (Niccalai et al., 2000, p. 187).

Another study by Adeneye et al. (2006) did a cross sectional survey in Nigeria of 804 women attending both private and public clinics. The main focus of the study was to assess the knowledge and perceptions of HIV/AIDS among women as well as to determine the usefulness of Voluntary Counselling and Testing (VCT).The results suggested that 72% knew that HIV was a sickness that existed in society whereas, 72% reported that they witnessed or knew somebody who died due to HIV/AIDS. Furthermore, 30.7% of the sample reported that it was significant to know their status. In contrast, a large number of the women (69.3%) had poor knowledge of their HIV status and did not see the usefulness or the significance of having voluntary HIV Counselling and Testing (VCT) centres". Of 723 respondents who had heard of HIV/AIDS, 504 (69.7%) did not understand the importance of knowing one's sero-status. Those 219 who knew the importance said, for example, it helps in deciding whether or not to have children (12.3%), helps explore family planning options (11%), promotes behavioural change (27.4%), facilitates prevention of MTCT (17.4%), enhances the opportunity to accept and cope with one's sero-status (20.5%), and presents an opportunity to be eligible for antiretroviral therapy (10.5%) and for early management of opportunistic infections (19.2%)" (Adeneye et al., 2006, p. 349). The study recommended the strong need for people to be educated about HIV and VCT to avoid more infections.

The studies presented above point out that there is a strong need for individuals to have knowledge around their illness or disease so that they can engage in healthy behaviours that will prevent further HIV transmissions. One may state that lack of knowledge about HIV or HIV diagnosis in infected and non-infected individuals is a major problem, since it hinders preventive measures and increases more infections. As shown by the studies presented above, the issue of knowledge or lack of knowledge is a universal concern facing people of all parts of the world; as a result these studies suggest that interventions should focus more on educating as well as creating awareness so that the progression of the pandemic can be reduced.

2.6.2 Acceptance

Chovwen and Ita (2006) point out that a lack of acceptance of an HIV diagnosis can at times be followed by negative consequences such as inability to access treatment, and can exacerbate the personal conditions of people living with HIV/AIDS thus leading to poor health. There are a number of studies that have been conducted in relation to people living with HIV/AIDS (PLWHA) and acceptance. A study by Chovwen and Ita (2006, p. 88) "investigates how people living with HIV (PLWHIV) in Nigeria perceive their acceptance by others in society, the possible influence of self-consciousness, perceived stigma on acceptance, and the possible gender differences in perceptions of acceptance". The study employed a qualitative approach, with a sample size consisting of 120 HIV positive individuals, both males and females. All participants had been diagnosed with HIV three to five years prior to the study. The results revealed that among HIV positive people, positive attitudes and self awareness play a role in enhanced acceptance of one's status and thus resisting prejudice from people. In addition, self awareness was more common in males as opposed to females because, "in many societies, females are relatively more vulnerable and often perceived to be the vector of the disease especially in heterosexual relationships" (Chovwen & Ita, 2006, p. 89). The study concluded that self awareness as well as stigma played a major role in determining an individual's level of acceptance of their HIV diagnosis.

One study viewed how acceptance of an HIV positive status can be used as a coping mechanism. In Namibia, Plattner and Meiring (2006) used a qualitative approach to explore how people living with HIV cope psychologically with the virus. Semi-structured interviews were used and were video-taped. The sample included eight female and two male participants ranging in age between 20 and 48 years. The results revealed that the participant's response to being HIV-positive was based on certain ideas. Firstly, the participants accepted their HIV-status in their lives because they felt they blamed themselves for contracting the virus and secondly, they associated their HIV status to God's will (Plattner & Meiring, 2006). The participants who accepted their diagnosis were able to settle and they were at peace with their diagnosis. Moreover, those who accepted their diagnosis managed to overcome the feelings of self blame and guilt that they had about the disease.

2.6.3 Grief and bereavement

According to Van Dyk (2001), individuals who are HIV positive have strong feelings of grief if they have witnessed the loss of loved ones. On the other hand, they have to cope with their life. Studies have emphasized how grief and bereavement is associated with HIV/AIDS. In a qualitative South African study, Demmer (2007) explored how 18 bereaved participants, 13 of whom were HIV positive, coped with HIV related loss. To be eligible for the study participants had to be 18 years or older and report an important relationship to a person or persons that had died of AIDS in the recent past. All participants reported that their way of grieving their AIDS related losses was by adopting coping strategies such as turning to their spiritual beliefs , holding back their resentful feelings as well as sustaining a positive and hopeful future about their lives (Demmer, 2007).

Another study by Demmer (2006) employed a qualitative approach to investigate the views of professional caregivers about HIV positive bereaved clients as well as their own experiences in dealing with HIV/AIDS related losses. The sample consisted of eight female professional caregivers recruited from nongovernmental organizations in Kwazulu-Natal. "Caregivers expressed difficulty in assisting clients with their grief due to several factors, including more-pressing client needs (such as economic survival), clients' reticence to talk about their grief, inadequate preparation for dealing with death and bereavement as professionals, and scarce organizational resources" (Demmer, 2006, p. 97). Moreover, study participants' recurrent contacts with HIV related loss was more likely to lead to exhaustion within their profession.

Another study was conducted at the United States of America (USA), in which Summers (2004) explored how bereavement is experienced in people living with HIV, as well as assessing their level of psychological stability. The sample consisted of 93 participants, 62 men and 31 women ranging in age from 18 to 49 years. The Grief Assessment Inventory, a structured clinical interview, the Hamilton Depression Scale as well as the Suicide Assessment Scale were used. The results suggest that men and women experience grief in distinct ways. Women were more likely to experience uncertainty, grief and more psychological disorders such as depression, anxiety and recurrent thoughts of suicide when compared with the men in the study. Grief, therefore, had a greater impact on the mental health of women than men.

Another study in the USA "explored the influence of gender and ethnicity on coping strategies of 252 bereaved, HIV positive individuals" (Tarakeshwar, Hansen, Kochman & Sikkema, 2005, p. 109). Measures included the Health Status Scale, Instrumental Support Evaluation, Coping Questionnaire, Coping with Illness Scale and the Grief Reaction Index. The results showed racial and gender differences in grief and spiritual coping among individuals living with HIV. For instance it was evident that white males rely more on spiritual coping during the process of grief than females. In contrast, within the African American group spiritual coping was more strongly associated with grief for women than men.

2.6.4. Denial

Van Dyk (2001) argues that most people who are HIV positive are likely to go through a period of denial mostly just after being told about their HIV diagnosis. She asserts that because an HIV positive diagnosis can be anxiety provoking, the majority of people go through the stage of denial as a way of reducing their emotional distress and to cope with this life threatening disease.

In contrast, Otiono (2008) maintains that high levels of denial act as a major barrier to accessing treatment, thus increasing the level of the pandemic as well as hindering the preventative measures required to fight the HIV virus. Furthermore, denial affects a vast number of individuals in society such as the churches, countries and families, and denial can exacerbate the occurrence of the virus due to the ignorance that people have around the circumstances of the virus. Otiono (2008) argues that Denial will result in causing more infections among infected HIV/AIDS individuals because they will not change their promiscuous behaviours, even when they present with physical signs or symptoms thus infecting many more people..

Meursing (1999), in a Zimbabwean study adopted a qualitative approach to explore the barriers that hindered 96 (58 women and 38 men) HIV infected individuals in practicing safer sex. Themes such as "women's lack of sexual decision-making power; men's dislike of condoms; denial of HIV" were identified (Meursing, 1999, p. 35) as major barriers that hindered safe sex practices amongst the participants. The results suggest that preventive programs can be effective only if they are designed in a way to encourage and promote acceptance and openness regarding HIV status. This study demonstrates how denial can facilitate the progression of HIV/AIDS.

In Botswana, using a qualitative approach, Nam et al. (2008) explored the psychosocial aspects linked to adherence to antiretroviral drug treatment among individuals who are HIV positive. The 32 participants were recruited from two public clinics and were all above 21years of age. Participants who were eligible for the study had to present with a CD 4 count of less than 200 cells/mm3 or had to present with early symptoms of AIDS. Among the overall sample, 23 participants reported experiencing difficulties in their adherence to medication, whereas nine of them stated that they did not encounter any difficulties regarding adherence. Individuals who accepted their diagnosis were associated with good medication adherence and had a sense of hope regarding their diagnosis. In contrast, participants who were in denial about their diagnosis were associated with poor medication adherence and presented with psychological conditions such as depression. The study concluded that "it is important to identify individuals with HIV who are still in some degree of denial about their status and to identify depression among patients on antiretroviral. This will enable more targeted, individualized support in the management of individuals' HIV disease" (Nam et al., 2008, p .302).

Ironson et al. (1998) examined the psychological conditions of HIV 30 positive gay men in the USA after they had learned that they were HIV positive. The measures used included the State Anxiety Inventory, Profile of Mood States, Impact Event Scale and Coping Scale. The results suggest that denial and distress, by facilitating the development of the life threatening disease, had a negative impact.

Another study in the USA, using a quantitative approach, focused on denial as a dysfunctional coping mechanism, and explored the link between compliance with antiretroviral treatment and social support and coping tactics amongst individuals with HIV/AIDS (Power et al., 2003). The measures used were the Medication Adherence Tool, Social Support Inventory, and the Brief Coping Inventory. The sample consisted of 73 individuals (both males and females). The results suggested that 74% of the individuals amongst the overall sample were adherent to medication, and adherence was associated with social support from family, partners and friends. On the other hand, 26% of the sample were not adherent, and demonstrated denial as well as avoidance in dealing with the disease. Moreover, avoidance behaviours such as alcohol abuse were linked to individuals who were non adherent. Stigma also played a role in their non adherence. The authors concluded that denial is a major barrier amongst people who are HIV positive and has a negative impact on accessing treatment.

2.6.5 Mental health and HIV

Brandt (2008 , p. 11) maintains that "mental health in developing countries is a long standing phenomenon and one that has become more deeply rooted with every new public health challenge" . Research has shown several links between HIV and mental health, including higher rates of mental illness amongst PLWHA, and since the pandemic is developing rapidly, developing countries are faced with massive mental health conditions in PLWHA. The World Health Organisation (2008) argues that the pandemic can create major psychological burdens on individuals living with the disease, with HIV infected people being likely to experience psychological disorders such as depression and anxiety. Furthermore, the mental disorders are often accompanied by challenges such as complications with living with the illness, resulting in reduced life expectancy, stigmatization, and loss of social support from family or friends (WHO, 2008).

A number of studies have demonstrated the association between mental disorders and HIV For instance, Tate et al. (2003) used a quantitative approach to explore the link between depression and quality of life among individuals infected with HIV in Chicago. The sample consisted of 45 HIV positive individuals (16 males, 29 females) recruited from an academic HIV care programme. The results showed that both lack of interest and depression were more common among patients with HIV than those individuals without HIV. Twenty-six percent of the patients with HIV reported that they experienced apathy while a staggering 80% reported depression.

Brandt (2008) reviewed quantitative research on the mental health of HIV infected individuals in Africa and found that infected HIV people experience psychiatric disorders such as substance abuse, post traumatic stress disorder and anxiety disorder, and that depression is the most commonly reported disorder. Brandt's (2008) review showed that most people living with HIV/AIDS were likely to have a higher prevalence of mental disorders if they were female, were not accessing ARVs, were experiencing poor quality health services, and were not receiving emotional support from friends and family.

Another study (Olley, 2006) explored the psychological responses associated with an HIV diagnosis among black African women. The sample consisting of 105 HIV positive black and coloured women between the ages of 18 and 35 years was drawn from an outpatient clinic for infectious diseases at Tygerberg Hospital in Cape Town. The measures used included the Mini-International Neuropsychiatric Interview (MINI), the Carver Brief COPE, and the Sheehan Disability Scale. The results suggested that 56% of the HIV positive women were likely to experience psychiatric conditions, the most common being "major depression (38.1%), followed by dysthymia (22.9%) and post-traumatic stress" (Olley, 2006, p. 212).

Freeman, Nkomo, Kafaar and Kelly (2007) examined the relationship between mental health and being HIV positive using a quantitative approach. The Composite International Diagnostic Interview and a structured interview were used to gather data from a sample of 900 HIV positive individuals. The results suggested that overall the prevalence of mental disorders such as depression, anxiety, PTSD and dysthymia was 43.7%, although it was higher (49.7%) in the last stage of AIDS.

Other studies have focused on the mental health of HIV positive women. One study conducted by Bernatsky, Souza and Jong in South Africa in which it, (2007) compared the mental health of HIV positive women attending an HIV clinic over a period of three weeks, with other groups of pregnant women. Among the overall sample, 42.6% reported that they had decided to conceal their HIV diagnosis, whereas 37.5% had disclosed to sexual partners. The women who were engaging in sex after diagnosis reported that they did not use preventive methods such as condoms; only three used such measures. "Two-thirds of the HIV positive women had significant emotional distress, more than twice that in the control group. As well as HIV status, marital status was a strong independent predictor of mental health status, with married women experiencing less emotional distress" (Bernatsky et al., 2007, p. 674). The authors concluded that effective interventions that target the stigma around HIV/AIDS need to be employed to deal with the mental health of women.

In the USA, Karolyn, Schrismshaw and Lekas (2006) used a qualitative approach to explore the link between HIV and sexual functioning, as well as feelings of attractiveness after diagnosis among HIV infected women who were in a HAART program. The sample consisted of two groups of women (146 and 138) ranging in age between 20 and 50 years. The results suggested that due to their HIV positive status, not only did the women's level of sexual desire lessen, hindering their ability to engage in sexual practices with their partners, but their feelings of attractiveness also lessened.

2.7 Interpersonal factors

The interpersonal level as defined by McLeroy et al. (1988, p. 355) includes "formal and informal social networks and support systems including family, workgroup and friendship networks", and these factors play a major role in shaping and modifying health related behaviours of an individual. Similarly, Power et al. (2003) argue that superior social support from family, peers, and friendship networks is likely to have a positive impact on the health of people with HIV, by, for instance, enhancing their ability to adhere to treatment or to practise healthy behaviours.

2.7.1 Disclosure

There are a number of studies that focus on the issue of disclosure. Pre´au, Bouhnik, Roussiaua, Lert and Spire (2008, p. 521) argue that "disclosure of one's HIV sero-positivity to significant others is often perceived as a double-edged sword because it may open up the opportunities for medical and social support, which may be critical in adjusting to the illness, but it may lead to extra stress as a result of stigmatization and discrimination and disruption of personal relationships".

Ncama (2007) points out that since in developing countries we are faced with limited resources, very few people are willing to disclose their positive HIV status to others and fewer people are openly living with HIV/AIDS. Taraphdar et al. (2005) maintain that sometimes disclosing one's HIV status can be followed by negative consequences and that HIV infected individuals can experience overwhelming emotions such as guilt, blame and rejection after disclosing their status; they may also receive reduced social support, and be denied assistance from family members because of the stigma attached to the disease, thus impacting on their mental health.

Préau, Bouhnik, Lert and Spire_(2008) demonstrated the negative outcomes of disclosure. Using a face-to-face questionnaire containing closed ended questions, they explored the relationship between religion and disclosure of HIV in couples. The sample, consisting of 2932 participants, was selected from 102 hospitals in France. All participants were 18 years of age and above and had to have been diagnosed 6 months prior to the study. The results suggested that participants who regarded religion as a significant aspect of their life were unable to disclose due to fear of stigma and discrimination. Furthermore, attitudes that people have about religious people hindered them from disclosing. The authors concluded that religion acts as a barrier for people to disclose their HIV diagnosis to their partners or significant others.

Conversely, many studies have revealed the positive impact of disclosure. Taraphalar, Dasgula and Saha (2007) assert that disclosure of HIV status is essential for several reasons: it can lead to improved social support as well as improved emotional well being of the individual living with the virus; it can facilitate and enhance treatment and prevention amongst individuals who are HIV positive; and it can help individuals to engage in safer sexual practices to avoid transmitting the virus. Similarly, Varga, Sherman and Jones (2005) maintain that while stigma and discrimination around HIV hinders disclosure, disclosing HIV status can enhance and induce better coping strategies of the individual in dealing with the virus.

Simbayi, Kalichman, Strebel, Cloete Hende and Mqeketo(2006) used a qualitative study to compare disclosure and non-disclosure of HIV status to sex partners, as well as the influence of non-disclosure on sexual risk behaviours among HIV infected individuals. All 903 participants were below the age of 35 years, with the majority being black Africans. The results suggested that individuals who did not disclose to their partners feared of being discrimination. The researchers concluded that stigma was a major obstacle to disclosure, and that future interventions should be designed to address the stigma to combat the pandemic.

A study by Bor (2001) explored the impact of diagnosis on the families of Greek individuals who were diagnosed as HIV positive. The study also explored how participants defined 'close family'. The sample, recruited from NGOs and a public hospital, comprised of 64 HIV positive individuals, 52% of whom were homosexual males. The questionnaire was divided into two sections: first section contained the family and disclosure questionnaire; and the second contained the definition of 'close family'. The results suggested that those individuals who disclosed their HIV diagnosis to close families (mothers, fathers, sisters and brothers) received enhanced social support that contributed positively towards both their physical as well as emotional wellbeing.

Another study, Skhosana, Struthers, Gray and McIntyre (2006, p. 17) "explores contextual factors — such as disclosure, preparation for treatment, treatment meaning and treatment acceptance — as aspects of lifestyle that can bear on adherence" among HIV positive individuals in Soweto (South Africa) who were currently accessing antiretroviral drugs. The data was collected using semi-structured interviews. One-on-one interviews were conducted with a sample of 38 HIV positive participants, 32 women and 6 men. The results suggested that the respondents who disclosed their status were able to receive social support from household members and were able to adhere to treatment and this helped them to accept ARVs as part of their daily life.

2.7.2 Social support and social influence.

Kalichman, DiMarco, Austin, Luke and DiFonzo (2003) asserts that social support plays a major role in shaping the health of HIV/AIDS infected individuals, and that social support reduces the strain of being HIV positive, thus improving physical as well as psychological wellbeing. Furthermore, Kalichman et al. (2003) maintain that social support provided to individuals is important because it helps HIV positive individuals to tackle the stress their might be experiencing, thus promoting their wellbeing.

A number of researchers have demonstrated that social support can improve the health of an HIV infected individual. For instance, Element (2006) investigated the differences in social networks and social isolation among older and younger adults living with HIV/AIDS. The sample consisted of 88 HIV positive individuals; the older adults were over 50 years of age, and the younger adults ranged in age from 20 to 30 years. Using interviews to collect data, the author found that older individuals were likely to live alone and did not receive much social support, whereas younger individuals were more likely to be granted social support by family and friends, thus positively impacting on their emotional and physical wellbeing. Moreover, adequate social support was associated with reduced discrimination and stigma which is associated with enhanced mental health amongst individuals living with HIV.

Similarly, Ncama (2007) asserts that Integrated Community/Home-based Care (ICHC) programmes can facilitate acceptance for HIV infected individuals. In a study in Zululand, South Africa, Ncama (2007) used both a qualitative approach using focus groups for the initial phase, and a cross-sectional survey using questionnaires to collect data amongst a group of 363 men and women ranging in age from 20 to 50 years, and living with HIV. Of the total sample 152 were served by the ICHC programme and 211 were not receiving any home-based care. The results suggested that individuals who were served by an ICHC were able to accept and disclose their diagnosis as opposed to the group who were not. This study demonstrates the impact of environmental support on an individual in making health related decisions.

Ncama et al. (2008) adopted a cross-sectional, descriptive study to explore the connection between social support and antiretroviral adherence among HIV positive individuals in KwaZulu-Natal. The sample consisted of 149 participants above the age of 18 years.

Measures used to gather data were: the Socio-demographic Questionnaire; MOS Social Support Scale; Morisky Adherence Scale; Perceived Non-Adherence Scale (ACTG). The results suggested that social support is essential in people living with HIV/AIDS because it facilitates medication adherence. However, obstacles indentified by participants as leading to non-adherence included stigma attached to disclosure of HIV status, alcohol abuse, as well as lack of basic needs such as food.

Yang, Xia, Li, Latkn and Celentano (2010, p. 71) contend that social influence has both negative and positive influences on an individual's health related behaviours, stating that "social influence is likely to influence sexual behaviours mainly indirectly through HIV information, prevention and behaviour skills". They assert that social influences that can facilitate risky HIV related behaviours could be factors such as gender norms and power in relationships, whereas factors such as peer or family support are likely to have a positive impact on individuals' health related behaviours. Yang et al. (2010, p. 72) maintain that "the gendered behavioural norms restrict women's sexual expressions, discourage open discussion within relationships, and limit women's access to HIV preventive information, and thereby increase their social exposure to unsafe sex". Norms that guide the individual can, at times, hinder them from engaging in healthy behaviours.It is apparent from the studies presented above that social influence as well as social support play a major role in shaping the health of an individual both positively and negatively.

2.8 Institutional factors

McLeroy et al. (1988) maintain that institutions share common standards and behaviours which are important for society to function. For instance, public services such as schools, hospitals and universities share common standards that have an impact on the health behaviours of individuals within the different institutions. The studies presented below serve to illustrate how organizations can influence health or health related behaviours of individuals.

Some studies have focused on how workplaces influence individual health behaviours. Fesko (2001) used a qualitative approach to explore the experiences of 18 HIV infected people as well as 14 individuals diagnosed with cancer. Interviews were conducted using open ended questions to better understand the advantages and disadvantages of disclosing in the workplace. The sample was recruited from an HIV organization, through local newspapers and self referrals. The results suggested that though some of the participants in both groups who disclosed to co-workers received positive reactions, both groups reported that they felt rejected and discriminated against at some point by co-workers. From the study it was evident that although people who were diagnosed with cancer and HIV shared common experiences, distinctive factors were evident; for instance, individuals diagnosed with cancer reported that they were likely to disclose their health status at work as opposed to HIV positive group. "In addition , individuals with cancer received more accommodations, sometimes even ones they did not request, and when their needs were not met, they were more likely to pursue legal recourse than individuals with HIV"(Fesko, 2001, p. 8).

Schools are another institution that has an influence on how youth experience illnesses like HIV/AIDS. James, Reddy, Ruiter, McCauley, and Van den Borne (2006) employed a quantitative approach to assess the development and implementation of HIV life skills programmes among Grade 9 learners in 22 schools in KwaZulu–Natal, South Africa. The life skills programmes also involved the training of teachers to help enhance knowledge regarding HIV/AIDS amongst the learners. During the implementation stage some teachers were able to complete the whole process whereas others partially implemented the programme. James et al. (2006, p. 291) concluded that "in total teachers used a didactic style more and reported comfort with teaching more fact based rather than skill based topics".

Bastien, Sango, Mnyika, Masatu and Klepp (2008, p. 382), using a quantitative approach, explored the "exposure to AIDS information, communication and knowledge levels from 1992 to 2005" among primary school children from 18 randomly selected schools in northern Tanzania. They found a high level of exposure to information and communication regarding AIDS in these primary schools due to the fact that schools adopted preventive programmes and policies, and educated students about the pandemic. The authors recommended that "interventions should aim to stimulate discussion in young people's social networks in order to increase overall exposure to AIDS information, communication and knowledge" (Bastien et al., 2008, p. 382). This study illustrates the significant role that schools can play in how young people come to understand an illness like HIV/AIDS.

2.8.1 Hospitals

Another institution that has an impact on the way in which individuals experience HIV/AIDS is hospitals. Adebajo, Bangbola and Oyadiran (2003) explored the attitudes and beliefs among 254 nurses and laboratory technologists towards HIV infected patients in Nigeria. A cross-sectional survey was adopted to measure participants' knowledge regarding HIV/AIDS, as well as their attitudes towards people living with HIV/AIDS. Only 39.4% of the overall sample had good knowledge around HIV/AIDS; 59.1% had fair knowledge; whereas, 3.5% reported poor knowledge. Problematically, 33.2% of the sample reported that people who were at higher risk of contracting the disease were sex workers and homosexuals. Half the participants failed to identify other higher risk groups such as adolescents. The majority of participants also reported HIV as a serious threat to themselves as health professionals. Of great concern was the large number (61.3%) of professionals who displayed discriminatory practices towards HIV infected patients. Adebajo et al. (2003) concluded that the study showed how health professionals within the hospital setting can have an impact on individuals' experiences of HIV/AIDS.

Another study by Reis, Heisler, Amowitz , Moreland, Mafeni and Anyamele (2005, p. 0743) aimed to " characterize the nature and extent of discriminatory practices and attitudes in the health sector and indicate possible contributing factors and intervention strategies". The study consisted of 1041 health professionals who were nurses, midwives and physicians in Nigeria. Survey questionnaires as well as interviews were utilized to collect the data. Of the overall sample, 67% consisted of females; the majority of the participants reported having some HIV training from courses that they had done as students, as well as from conferences. Reis et al. (2005 p. 0746) reported problematic findings; for example, over 50% of professionals reported obtaining informed consent of patients for HIV tests half of the time or less, including 14% who reported never obtaining consent for HIV tests'. The health care professionals presented with discriminatory attitudes towards HIV patients; for example, 91% of the professionals reported that they felt it was fair to be told if the patient was HIV positive so that they could be careful when dealing with such patients; 46% of the professionals reported that they believed HIV patients should be separated from other patients by having beds that would distinguish them from other patients; and 20% of the professionals stated that these HIV patients were deserving of the disease because of the risky behaviours they had engaged in. The study also showed that a majority of health professionals engaged in discriminatory as well as unethical behaviours towards HIV infected patients. The study concluded that lack of knowledge around HIV/AIDS and using safe sexual measures to contributed to attitude of the participant's (Reis et al., 2005, p. 0746). This study illustrates how institutional practices like lack of training and limited resources can have an impact on the way in which staff treat patients.

2.9 Community factors

McLeroy et al. (1988) argue that a community can have a major influence in marginalising disadvantaged groups such as HIV individuals because of the authority it holds in society. Therefore one can state that community factors can have both negative as well as positive impacts on individuals in addressing their health concerns.

2.9.1 Stigma and Discrimination

"HIV/AIDS is perhaps the most stigmatized medical condition in the world" (Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007, p. 1823). Herek and Capitanio (1993) assert that since the HIV/AIDS epidemic has been known, stigma and discrimination have been very common with the diagnosis of HIV. Chovwen and Ita (2006) point out that negative attitudes and behaviour from non-infected persons towards people living with HIV are very common and continue affecting the wellbeing of infected individuals, often raising psychosocial concerns that create tension in an individual's mental health. Furthermore, the level of stigma and discrimination is widening and continues to be associated with HIV infection and AIDS illness in the world (Chovwen & Ita, 2006). Stigma and discrimination against people living with HIV/AIDS hinder their ability to deal with their own illness, creating misery and strain, hindering their ability to enjoy life, and impacting negatively on their wellbeing (Delius & Glaser, 2005).

Parker and Aggleton (2002, p. 354) maintain that "stigma and discrimination occur in a variety of settings and at all levels of society as well as involves compulsory screening and testing, compulsory notification of AIDS cases, restrictions to the right of anonymity, prohibition of PLWHA from certain occupations, and medical examination, isolation, detention and compulsory treatment of infected persons". Theron (2005) argues that stigma is influenced by a variety of aspects such as lack of awareness about the disease, fear of death and disease, and cultural aspects. Theron (2005, p. 57) highlights some of the myths people hold about HIV:

- HIV is considered a punishment from God
- HIV is caused by sorcery, witchcraft or ill-will
- HIV can be casually transmitted which engenders fear of HIV positive individuals
- HIV results in painful death and therefore HIV positive individuals must be avoided.

In the context of HIV and AIDS, studies have shown that stigma impacts on prevention. Duncan, Harrison, Toldson, Malaka and Sithole (2005) used a cross sectional survey to explore the relationship between social stigma, HIV knowledge, and sexual risk behaviour among 169 South African and 145 black African American college students. A questionnaire consisting of Likert type questions was used to collect the data. The results showed that South African college students held low perceptions of stigma towards people with HIV/AIDS and were aware of condom use. Males from both groups were more likely to engage in high sexual behaviours, whereas females from South Africa were more likely to be at higher risk of contracting HIV/AIDS as compared to the American students.

Studies on stigma in relation to HIV/AIDS have focused on the link between stigma and mental health. For instance, Wingood et al. (2008), using a cross sectional survey including interviews, questionnaires, an HIV stigma scale, and a Depression scale, explored the impact of stigma on the mental health of 120 black women residing in the Western Cape. The results showed that stigma was associated with mental health aspects such as depression, poor quality lifestyle, the fear of disclosing their diagnosis to others, and post traumatic stress disorder.

Simbayi et al. (2007) adopted a quantitative approach to explore the link between internalized stigma and psychological problems among HIV infected people. The participants were 420 HIV positive men and 643 HIV positive women in Cape Town, South Africa. The results suggested that 40% of the sample experienced discrimination which was likely to be associated with psychological problems such as depression, drug abuse as well as alcohol abuse. More than half the sample (60%) stated that because there was so much discrimination attached to being HIV infected, they were not able to disclose their status due to fear of rejection by society. Furthermore, lack of disclosure regarding their status hindered them from accessing treatment. "These results indicate an urgent need for social reform to reduce AIDS stigmas, and the design of interventions to assist people living with HIV/AIDS to adjust and adapt to the social conditions of AIDS in South Africa" (Simbayi et al., 2007, p.1823).

A study in India (Chakrapani, Newman, Shunmugam, Kurian & Dubrow, 2009), using a qualitative approach, examined what hinders HIV positive sex workers from accessing ART provided at government centres. Focus groups and interviews were utilised to obtain data from 19 female sex workers aged 21 to 48 years. The results indicated that among HIV positive sex workers, stigma and discrimination from society played a major role in hindering them from accessing treatment because they feared disclosing their status. Secondly, they were likely to be discriminated against by health care providers. The authors concluded that the only way forward was to plan interventions that would deal with the stigma.

2.9.2 Gender issues

Hallman (2005) argues that gender, inequality especially in continents like Africa, can be a major risk factor in HIV/AIDS, acting as a barrier to preventing HIV/AIDS. Gender norms which are likely to increase the spread of HIV include aspects such as polygamy, economic deprivation in women, as well as deeply traditional practices. These factors play a significant role in widening the gap of inequality between male and female relationships, resulting in women being at higher risk of contracting HIV, although norms promoted by society also place men at risk of contracting HIV (Nattrass, 2006).

Wodi (2005) argues that there are several factors that facilitate or promote gender inequality in developing countries; for instance, lack of women's access to education, and cultural practices that favour men in decision making. Topics related to HIV/AIDS are disregarded in most African countries since they represent a sign of impurity to the society, preventing people from gaining awareness about the disease (ibid).

Studies have focused on gender relations and how gender associations impact on or contribute to HIV infection. For instance, Ndinda, Uzodike, Chimbwete and Pool (2007) assessed the views of both genders about proposed prevention methods amongst females. The study conducted in KwaZulu-Natal (South Africa), consisted of 11 focus groups among men and women in both rural and semi-urban areas (including a township). The focus groups comprised 6-16 participants. The major themes that emerged with regard to gender relations included the right of women to initiate love, childbearing and contraceptive rights for women, the right of women to refuse sex, and the conditions under which women may refuse to have sex. The results suggested that both women and men had a right to initiate sex and both genders play an important role in child bearing decisions. However, men pointed out that women, especially those who were married had to fulfil cultural norms and expectations and were not allowed to refuse sex; an exception was only to be made when a female was sick.

Another study, Arrivillaga, Ross, Useche, Alzate and Correa (2009), adopted both qualitative and quantitative approaches to explore the relationship between adherence to treatment and the social situation amongst 269 women living with HIV/AIDS in Colombian cities. These women were recruited from health care centres and NGOs. The measures included the Sociodemographic and Clinical Survey, Treatment Adherence Scale, and the Social Position Scale. The results showed that women of low social position were associated with poor adherence to treatment. Arrivillaga et al. (2009, p. 502) concluded "the findings emphasize the need to collaborate variables related to gender inequality and social position "

2.9.3 Minority groups

Kelly et al. (2004) assert that most marginalized groups infected with HIV are denied access to proper treatment and social care services due to the stigma and discrimination attached to minority groups.

In a USA study, Catz, Falton and Mcclure (2000) examined psychological distress among minority and low income women living with HIV. A sample of 100 women, at least 18 years or older, receiving medical care at an outpatient HIV hospital was chosen. Measures such as the Depression Scale, Trait Anxiety Inventory, Social Readjustment Rating Scale, Social Evaluation List, and the Coping Questionnaire were used to collect data. The results showed that most women were from minority groups and were experiencing high levels of distress which was likely to facilitate mental problems; for instance, most of the women presented with anxiety and depression symptoms. They received little social support from others.

2.10 Public policy

2.10.1 Public policy

McLeroy et al. (1988) assert that public health policy is a set of rules, actions and laws managed by governments and aimed at dealing with populations to address health or health related concerns. These policies can target the behaviour of individuals by using incentives to improve health or limit unhealthy behaviours to promote effective and better health.

According to Mchombu and Mchombu (2007), HIV/AIDS has had a devastating effect on individuals in Africa; however, most countries within the continent have responded to this pandemic by drawing up policies to address HIV/AIDS. Most of these policies tend to focus mostly on prevention and awareness campaigns, although some policies do focus on providing treatment (ARVs) to HIV positive individuals. However, limited funding in most African countries has served to reduce or restrict access to ARVs or treatment. Similarly, Hardon (2005) is of the opinion that most African countries are poorly resourced and ARVs are considered to be very expensive. "In 2000, following global campaigns to lower the prices of ARVs, and concern about the political instability caused by AIDS in Africa, policies started focusing on access to treatment" (Hardon, 2005, p. 601). However, within the continent, some countries such as Tanzania and Senegal have managed to adopt different as well as effective methods to help lessen the infection; for instance, in Senegal effective preventive methods were evident in the reduction of sexually transmitted diseases (STDs) (Mchombu & Mchombu, 2007). Other countries such as Bostwana, proved the effectiveness of adopting awareness campaigns to respond to HIV/AIDS because the "speed of Government response to the threat meant that people had to believe in the health promotion messages before they had any experience of the disease in their own lives" (Allen & Heald, 2004, p. 1144).

2.10.2 Policies that address HIV /AIDS concerns in Africa.

In South Africa, various policies to address HIV/AIDS have been adopted over the years; for example, in 2003 the government's plan for HIV/AIDS focused primarily on promoting prevention methods to combat the pandemic(Copper, Morroni, Orner, Moodley, Harries, Cullingworth, and Hoffman 2004). These methods included condom promotion as well as voluntary testing and counselling. Moreover, "In late 2003, the government approved a plan to implement public sector antiretroviral treatment (ARV) for people with AIDS, proposing to have at least one treatment site in every local municipality within five years" (Cooper et al., 2004, p. 78).

According to the HIV and AIDS Strategic plan for South Africa (2007-2011), some of the main goals were to:

- reduce the number of new HIV infections by 50%.
- reduce the impact of HIV and AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of all people diagnosed with HIV

In order to reach these aims, the main areas that need to be focused on are prevention, treatment, care and support, human rights, as well monitoring and conducting reach within areas of HIV/AIDS in South Africa (HIV and AIDS Strategic Plan, 2007). In particular, a recommendation was that young people in the age group 15-24 years should be a focus of all the interventions, especially those for behaviour change based prevention.

Heald (2005) points out that in some countries such as Botswana, ARV policy was adapted to people living with the pandemic and who had a CD4 count of less than 200. The aim of adopting such programmes was "to advance behaviour change by breaking the cycle of denial, infection and death" (Heald, 2005, p. 7). Though ARV therapy was viewed as a useful approach to deal with the pandemic in Botswana, Heald (2005) maintains that challenges that can hinder its effectiveness can arise in other developing countries. These challenges include lack of resources such as limited testing facilities, which can lead to large numbers of people not being reached, as well as stigma and discrimination which prevent people from testing. Furthermore, rolling out ARVs can be very expensive which can disrupt the sustainability of these programs. One may argue that although policies are developed to address the pandemic, challenges in implementation can arise in Africa due to a lack of resources and under-developed health facilities.

2.10.2 Policies to address HIV/AIDS orphans

Case, Paxson and Ableidinger (2004) report that in Africa, through the help of donors, policies have been adopted to respond to concerns about HIV orphans. For instance, in Zimbabwe, the Family AIDS Caring Trust (FACT) was established to identify and observe vulnerable affected AIDS orphans through "regular household visits; community ownership; keeping children in school; income generating activities; and volunteer training and motivation" (Phiri & Webb, 2002, p. 21). Volunteers identify the needs of these children and provide support such as food or clothes. Another example is the Community-based Options for Protection and Empowerment (COPE) project in Malawi, which involved the community as well as organizations to address the needs of AIDS affected children by including identification, monitoring, assistance and protection of orphans as part of community activities (Phiri & Webb, 2002).

Using the ecological framework to review some of the HIV/AIDS literature has enabled an analysis of the various levels of influence that impact on the way in which an illness like HIV/AIDS is experienced. The ecological model moves away from blaming individuals for their behaviour and recognising the role of environmental factors on health related behaviour. Nelson and Prilleltensky (2005, p. 73) argue that the ecological model is critical of mainstream psychological models that have "focused too much on individual psychological processes and neglected the important role that social systems play in human development". They go on to contend that from the ecological perspective one needs to "understand the pathogenic or oppressive qualities of human environments – those that block personal growth and create problems in living – and the positive qualities of environments that promote health, well-being and competence". A review of the HIV/AIDS literature framed by the ecological framework has enabled a much more integrated and holistic understanding of the experiences of people infected and affected by HIV/AIDS. A review of the literature from a traditional psychological framework would have perhaps been limited to the inter and intra personal levels of analysis. The ecological framework, however, moved the analysis beyond the level of the individual by taking into consideration the wider human environment in which people are embedded and with which they have a dynamic relationship.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Qualitative interpretive design

In this chapter the research design, sampling technique and sampling size, data analysis as well as ethical considerations are discussed.

For this study I employed a qualitative, interpretive method, which adopts a theoretical thematic approach to analysis. Braun and Clarke (2006, p.6) define thematic analysis as “a method for identifying, analyzing and reporting patterns (themes) within the data”.

Struwig and Stead (2007) assert that qualitative research methods can be used to gain insight into people’s attitudes, behaviour, value systems, concerns, motivations or aspirations. Similarly, Ulin, Rebinson and Tolly (2005, p. 4) contend that qualitative research is an approach that serves to “focus on complex relations between personal and social meanings, individual and cultural practices and material environment and context”. This approach aims to understand people’s experiences.

Stead and Struwig (2007) highlight four characteristics of qualitative research. Firstly, qualitative research focuses on the participants’ perspective and the analysis and interpretation is based on the participants’ views on their experiences. Secondly, contextualism is stressed when adopting qualitative research because it “emphasises the various macro and micro contexts of the individual and how these contexts dynamically interact with one another” (Stead & Struwig, 2007, p. 12). Contextualism focuses on the social contexts and how these contexts affect or influence people’s ideas, experiences or health. The third characteristic of qualitative research is that it is process research which “examines interrelated events along a temporal and developmental continuum” (Stead and Struwig, 2007, p. 12). For instance the qualitative researcher is aware that people’s experiences and behaviour are not stable and, therefore, process and change are important. Lastly, another characteristic of qualitative research according to Stead and Struwig (2007), is that it is flexible in terms of using theories. Qualitative researchers "tend to be mistrustful of theories and prior research, partly because research participants and their different contexts could be different in research literature. They may argue that as the study progresses, so does their use of theories and research" (Stead & Struwig, 2007, p. 13).

My study adopted a qualitative approach and drew on the ecological theoretical framework to understand the experiences of HIV infected and affected individuals. This enabled an analysis of how each level of the ecological model influences the participants who are infected and/or affected by HIV/AIDS. In this way my study recognises the importance of contextualism in qualitative research by taking into account the social context in which the participants are embedded. By focusing on the stories of the participants my study also recognises the importance of the participants' perspectives and experiences.

The qualitative approach is well suited to this study because the study serves to look at how all the levels of analysis within the ecological model come together to impact on the way in which individuals experience illness. As it has been pointed out, this approach is best at giving rich explanations of complex experiences in a given population (Stead & Struwig, 2007). Furthermore, it allows subjective human experience to be explored in detail and is different to studies that use quantitative research designed to measure and quantify the experiences of individuals.

3.2. Data collection

Fourteen stories of HIV infected individuals were selected from the text entitled *28 stories of Aids in Africa.* The book was written by Stephen Nolen, a journalist and AIDS reporter.

Nolen (2007) wrote the book after being inspired by an HIV positive woman whom she had met at a local AIDS organization in Malawi and who shared her experience of living with the virus. Nolen (2007) describes how she travelled across Africa to collect stories and argues that "reporting on AIDS is different. You don't get in and get out on a story like this: you get in, and sit down, and start a very long conversation. AIDS is not an event, or series of them; it's a mirror held up to the cultures and societies we build" (Nolen, 2007, p. 4). Nolen chose Africa because it is one of the continents which have been reported to have the highest rate of HIV/AIDS in the world. Many of the people she met suffered various levels of loss including betrayal by their lovers, government, families and neighbours, yet many of the people told stories of resilience and hope. As Nolen (2007, p. 17) states, "these stories of triumph and resilience, give cause and hope in the most unlikely circumstances".

I need to acknowledge that the data used in this study is 'secondary data' as the "narratives have already been collected and, to a certain extent, interpreted and analysed through the story writing process of Nolen (2007) in her capacity as a journalist" (Kadwa, 2010, p. 39). In analysing Nolen's (2007) stories for her own research, Kadwa (2010) argues that there is compelling evidence for the use of secondary data in qualitative research. She maintains that using secondary data is resource efficient, and maximises the use of existing data. She describes how this enabled her to access the stories of participants across Africa without having to actually travel and interview them. This is the case in my research. I, like Kadwa (2010) did not have the funds to travel across Africa to interview individuals. This was also time efficient. As a master's student expected to finish my study in a limited amount of time, using Nolen's (2007) pre-existing stories meant that I did not have to interview the participants directly nor go through the very timely process of transcribing interviews.

3.3 Participants

The stories chosen included the lived experiences of individuals affected and/or infected by HIV/AIDS, as well as the impact that the disease has had on these individuals. All participants were from African countries: Godfrey and Peter from Zambia; Lili from Botswana; Lebo from Lesotho; Martha from Uganda; Iran from Nairobi; Zack and Thabo from South Africa; Tom from Zambia; Fred from Malawi; Rebecca and Molly from Zimbabwe; and Sonia and Joe from Ethiopia. Five of the participants were females and nine eight were males. Godfrey, Lili, Molly, Zack, Peter, Thabo, Lebo, Martha, Ana, Fred and Iran were HIV positive; Rebecca was an elderly HIV caregiver; Sonia and Joe children affected by HIV. Lebo was the only HIV positive child. The participants were all black Africans.

3.4 Data analysis

Kadwa (2010, p. 39) acknowledged that the stories that she analysed for her study had "already been exposed to a level of analysis and interpretation through Nolen's (2007) story writing process". Kadwa (2010) refers to the work of Andrews (2008) who contends that secondary analysis is a complementary process where new layers of meanings can be added to existing understandings. In my research therefore, I have engaged in a process of 'secondary analysis' adding new layers to the meanings and interpretations of Nolen (2007).

Struwig and Stead (2007) assert that data analysis methods enable the researcher to organise and bring meaning to a large amount of data. The method of data analysis in my study is thematic analysis, which Braun and Clarke (2006, p. 79) define as a "method for indentifying, analysing and reporting patterns of (themes) within data", maintaining that this method explains the data in great detail. Similarly Rubin (cited in Braun & Clarke, 2006, p. 80) claims that thematic analysis is exciting because "you discover themes and concepts embedded throughout" your data.

Braun and Clarke (2006, p. 86) describe thematic analysis as a "recursive process, where movement is back and forth as needed and is a process that develops over time". They caution that analysis guidelines are not a set of rules and that they therefore need to be approached with flexibility. My analysis is an adaptation of the six phases of analysis recommended by Braun and Clarke (2006) and which are described below.

3.4.1. Phase one: familiarising myself with the data

Braun and Clarke (2006, p. 16) recommend that it is important to start the process of analysis by immersing oneself in the data. They assert that immersion "usually involves 'repeated reading' of the data, and reading the data in an active way – searching for meanings, patterns and so on". I therefore began the process of analysis by reading each of the stories repeatedly. Braun and Clarke (2006, p. 12) contend that there is a difference between "inductive or 'bottom up' and theoretical or deductive or 'top down'" analysis. I adopted a theoretical approach to the analysis of my data because I used the ecological model to analyse the stories and therefore had pre-existing theoretical codes that informed how I read and searched for meaning and patterns in the data. My pre-existing theoretical codes were the different levels of analysis of the ecological model: the interpersonal, intrapersonal, institutional, community and public policy levels. I used pens in different colours that represented each of these levels of analysis, and as I read the stories, I highlighted extracts that I felt reflected these different levels of analysis.

3.4.2 .Phase two: generating initial codes

Phase two was not separate from phase one. In phase one I had already begun to code my data and so phase two involved a deeper level of coding and organizing of my data. I now used different sheets of papers which were headed with the different levels of analysis of the ecological framework, and listed extracts verbatim under these headings; for example, when I found an extract that I felt reflected the intrapersonal level of analysis of the ecological framework, I transcribed this quote verbatim under the heading 'intrapersonal factors'. In effect, I had pre-identified codes and then I attempted to match these codes with extracts from the data.

3.4.3. Phase three: searching for themes

This phase of the analysis involved taking the codes and focusing on searching for themes and sub-themes. My over-arching themes had already been decided because my analysis was theoretically driven, that is, the main levels of analysis of the ecological model (and my initial codes of analysis) became my over-arching themes. The six over-arching themes were: interpersonal factors, intrapersonal factors, institutional factors, community factors, and public policy factors. Under these themes I had numerous extracts that I felt demonstrated these main themes. This phase of the process of analysis, therefore, involved searching for sub-themes amongst the extracts that were recorded under the over-arching themes; for example, I had to look for the sub-themes under the over-arching intrapersonal theme, under which I found the following sub-themes: knowledge, denial, acceptance, emotional responses, resilience and experiences of death.

3.4.4. Phase four: reviewing themes

Reviewing themes, it is a phase whereby themes gets broken down in to what should be included and what theme should be discarded, of which those that are included answer the research question. It was during this phase of the analysis that I worked to break down the sub-themes into further sub-themes; for example, under the over-arching theme of 'intrapersonal factors', I identified the sub-theme of 'knowledge'; at the phase of refining these themes, I identified two further sub-themes under 'knowledge', that is, 'knowledge prior to diagnosis' and 'knowledge after diagnosis'.

3.4.5. Phase 5: Defining and naming themes

Because my analysis was theoretically informed my main over-arching themes were already named at the coding stage of the analysis process. It was at this point that I worked at naming the sub-themes and then began to work at trying to clarify what each theme was essentially about. For each theme and sub-theme, I identified relevant and appropriate extracts and then wrote an analysis for each one. Braun and Clarke (2006, p. 22) advise that "as well as identifying the 'story' that each theme tells, it is important to consider how it fits into the broader overall 'story' that you are telling about your data" . This phase of the analysis, therefore, involved trying to move beyond verbatim quotes and paraphrasing and trying to pick up on the story that the data was telling in relation to my research questions.

3.4.6 .Phase 6: Producing the report

The final phase of my analysis is presented in Chapter Four, Analysis and Discussion where I have tried to provide enough evidence in the form of extracts to provide "a concise, coherent, logical , non-repetitive, and interesting account of the story" (Braun & Clarke, 2006, p. 23) that my data tells. I have attempted to relate my analysis to previous research and the broader theoretical framework so that the analysis goes beyond just a description of the data.

3.5 Ethical considerations

Permission was obtained in writing from the publishers of Nolen's (2007) book (Portobello Books Ltd) and submitted with the ethical clearance application to the Ethics Review Committee of the University of KwaZulu-Natal which granted permission to conduct the research study.

In her research, Kadwa (2010) noted the ethical dilemma of using stories in which individuals' real names and demographic details have been publicly disclosed. Nolen (2007), whose book is located within the public domain and accessible to a wide audience, discloses the personal details of each individual and includes a photograph and demographic details. Kadwa (2010) refers to the work of Mauthner, Mc Kee and Strell (2001) who argue that where demographic information has already been made public it is pointless to completely conceal this information in a research report. After considering this argument, Kadwa (2010) decided that because she could not personally obtain the consent of each individual in the stories, she would use pseudonyms and would not include photographs or page numbers for the extracts from the stories. Although the people in Nolen's (2007) stories had consented to their details being made public, my supervisor and I believed that it was important to deal with this issue with caution. I decided to do what Kadwa (2010) had done, that is, using pseudonyms, and not including photographs or the page numbers of the extracts. I have, however, provided some demographic details including the country of origin, HIV status, gender and age of the participants. I believe that by using a pseudonym and taking steps to make it difficult to identify individuals in the stories, I have attempted to protect their anonymity and therefore respected their right to some degree of confidentiality.

My dissertation has employed an interpretive paradigm because, as pointed by Terreblanche Terre Blanche,& Durrheim, (2007) that the interpretive paradigm involves taking people's subjective experiences seriously and making sense of these experiences by listening carefully to what they tell us. Similarly, Ulin (2007, p. 18) maintains that the "interpretive perspective is a paradigm that sees the world as constructed, interpreted, and experienced by people in their interactions with each other and wider social systems. It focuses not on objective facts but also on many subjective meanings that people attach to them".

CHAPTER FOUR: ANALYSIS AND DISCUSSIONS.

In this chapter I present an analysis and discussion of the findings from my study.

4. Intrapersonal factors

4.1. Knowledge

4.1.1 Knowledge prior to HIV diagnosis

According to Nolen (2007) many of the participants lacked comprehensive knowledge with regard to HIV, which made them reluctant to test even though some of them were presenting with symptoms. Few participants voluntarily went for testing and only tested if forced by circumstances. This illustrates the realities about the fear of testing. In the following extract, Nolen (2007, p. 227) speaks about the circumstances that led to Godfrey finding out his status:

> *He had political ambitions and in 1990 won a scholarship for six months of a political science course in Leningrand. His visa application involved a routine medical, including an HIV test. He would never have tested otherwise, Godfrey said, "I wasn't entirely naïve about what it meant". A former girlfriend had died the year before of AIDS, although no one said so at the time, so when he went for his test, 'I was hoping against hope'. The hope was denied.*

While Godfrey acknowledged that he was not entirely naïve, his former partner's status had never been openly acknowledged and his possible risk had clearly not been addressed.

Nolen (2007, p. 137-138) also speaks of Lili from Botswana who did not test even though she was extremely ill:

> *And she started to get sick, black lesions appeared on her face, and she lost more and more weight off an already lanky frame. She saw a series of doctors and each advised her to have an HIV test. She flatly refused. Pretty young women with college degrees didn't get HIV- the disease was for poor people, people back in the village with straw for roof and chickens in the yard.*

In the above extracts it is evident that Godfrey was forced by circumstances to test. Although his former girlfriend had died due to AIDS, he was still reluctant to test, revealing the fears and anxieties associated with HIV/AIDS. For Lili, it is apparent that she had limited knowledge about the disease because she perceived HIV as a disease that only infects poor people and not academics. In both cases a level of denial is evident. In both Godfrey and Lili's case due to lack of information protected them from having to confront their own possible risk of HIV. It was only when Godfrey was forced to test that he found out his status and it was only when the physical symptoms manifested that Lili was forced to confront the possibility of an HIV status.

Nolen (2007, p. 277) discusses the case of Tom who claimed that the main reason he became infected was because he lacked information:

> *"There is not one time I ever felt guilty about my status", he said. "The only regret I have is that I lacked information. I have two degrees, one first class but I failed the HIV test. As word spread, there was one thing everyone wanted to know, how he got infected. "I always say I am a priest who did some good things like some of `Iyou and failed in some like others. But because I lacked information, I got infected".*

It is apparent from the above extract that although Tom was well educated in other aspects of his life (he held two degrees), he lacked awareness or information around HIV which resulted in him getting infected.

The following extracts also illustrate how many of the participants knew very little about HIV/AIDS. Nolen (2007, p. 367) discusses the case of Thabo:

> *"The first time I heard about HIV was in 1987 the biology teacher mentioned it: Human immunodeficiency something, the word was so long. The teacher said it was an incurable disease, sexually transmitted but mostly found among homosexuals".*

Nolen (2007, p. 137) writes of the limited knowledge that Martha had about HIV/AIDS:

> *She heard about rumors of HIV, but she didn't worry too much. "I thought, I won't get it I am young and beautiful and not a class to be infected.*

In the following extract Nolen (2007, p. 277) highlights how could have adopted healthy behaviours if he had had knowledge of HIV/AIDS:

> *He doesn't know when it happened: he and Mandy did not test before marriage, so either of them might already have had the virus.*

In the above extracts it is apparent that Thabo and Martha knew very little about HIV and believed in certain myths about the disease, such as, that HIV only affects homosexuals and that it is an incurable disease as well as associating it with people of lower class or older individuals. In the last extract, Nolen makes reference to how Godfrey's, Tom lack of awareness of HIV prevented him and his wife Mandy from testing for HIV before marriage. The extract illustrates the significance of HIV information among couples as a way to promote safe behaviours or preventive methods to avoid HIV. Adeneye et al. (2006) note that knowing one's HIV status helps in making important decisions such as using preventive methods to avoid the spread of disease as well as improving the health condition of an individual.

Research on HIV/AIDS suggests that knowledge is a powerful factor and a guideline that directs individuals' lives and shapes their positive wellbeing. Adeneye et al (2006) assert that poor knowledge with regard to HIV is often associated with higher levels of transmission and the consequences of poor knowledge can hinder individuals from using preventive methods such as condoms when engaging in sexual activities. These authors found that women who knew their HIV status were able to plan for their future and avoid risky health behaviours, thus enhancing their health.

4.1.2 Knowledge of one's status after diagnosis

In the following extract Nolen (2007, p. 364) describes the case of Thabo and how knowledge of his own status facilitated disclosure to his girlfriend:

> *...he decided it was time to go for an HIV test although he never entertained the idea that he might be positive. When the counselor said the word he thought immediately about suicide. Then he had another thought: what about his lovers? Could he have infected anyone else? If the women were at risk he felt he had to tell them before he did anything. His most pressing concern was for his close friend Sarah whom he had dated for a couple of years. They had a condom break a couple of times and he was consumed with fear that he might have infected her with HIV. So he went to see her that night, and told her the news. She was, as always, staunchly supportive, much more concerned for him than her own health. She tested that following day and again a few weeks later, and was negative both times.*

In the above abstract it is apparent that Thabo's knowledge about his own HIV status resulted in his disclosure to his ex-partner to establish whether he might have infected her. His first reaction to his positive status was thoughts of suicide. His other major concern was to try and ensure that he had not infected his previous sexual partners. Marks, Burris and Peterman (1999, p. 298) contend that "most seropositive people feel a unique sense of responsibility to protect sex partners. They know that it is wrong to endanger others by exposing them to HIV without their knowledge. This is most evident when there is emotional involvement with a partner and commitment to an ongoing relationship". Similarly, Niccalai, Farley, Ayoub, Magnus and Kissinger (2002) assert that knowledge about a partner's infection status is significant, because it rejects the assumptions that sexual partners can have about each other, thus decreasing HIV transmission.

In the following extract Nolen (2007, p. 54) discusses how Fred's knowledge regarding his positive status resulted in his disclosure and influenced his wife to test, as well as impacting positively on his own behaviour:

> *Mary went for an HIV test after he told her his results and she tested negative. Since then, he said they don't have sex, and he has given up sex on the road as well.*

Knowing their own status enabled significant people in both Thabo and Fred's lives to find out their own status and in Fred's case to change his own risky behaviours. Adeneye et al. (2006) remark that knowledge regarding one's HIV status enables better health and facilitates the process of testing for HIV among individuals. Furthermore, Adeneye et al. (2002) found that HIV infected women who had knowledge about their sexual partner's status were able to practise safer sexual behaviours, enhancing their ability to cope with their HIV status. Hence, knowledge of one's status promotes awareness and early knowledge can prevent the spread of the virus to other people as well as enhancing healthy sexual behaviours.

4.1.3 Knowledge of one's positive status associated with death and loss of hope

According to Nolen (2007), some of the participants associated their HIV status with death and loss of hope, as illustrated by the following extracts:

After being diagnosed with HIV Lili said:

> *"I'm still waiting to die but I don't die"* (Nolen, 2007, p. 141).

Zack's reaction to his diagnosis was as follows:

> *His test came back positive. "The doctor gave me six months to live," he recalled. He was twenty seven. He retreated into his house, drew the curtains, rented every movie he had ever wanted to see and waited to die* (Nolen, 2007, p. 181).

When Godfrey was told he was HIV positive, he reacted as follows:

> *Godfrey headed home from the clinic, passing garbage bins in the street emblazoned with skull and crossbones and the words 'AIDS kills'. For the next few days he sat in*

> *the small room he was renting with his brother Sam and wrote dark, despairing poems about having his life brutally truncated. After a week holed up at home he thought he would try to find a place to publish them before he died* (Nolen, 2007, p. 227).

It is evident that Lili, Zack and Godfrey believed that being HIV positive was a death sentence, leading them to experience overwhelming fear about their status. Further, their diagnosis was associated with a loss of hope since there is no cure and so much stigma attached to the disease. Both Zack's and Godfrey's perceptions of life changed after the diagnosis and both experienced immense despair. Lili, Zack and Godfrey all believed that they would die in the near future. This is likely to reflect what they thought about HIV/AIDS before they knew their own status. Fear, uncertainty and death are often associated with the virus.

4.2 Denial

4.2.1 Denial as a coping mechanism

The following extracts illustrate how denial was experienced by the participants. Nolen (2007, p. 80) writes about Lili, a doctor, who was in denial about her own HIV status despite knowing the symptoms of HIV:

> *And so even though she was a doctor who could clearly recognise the symptoms, she refused to consider that she might have the virus. But when she checked in to convalesce, the staff, without consulting her, tested her for HIV. She was positive.*

Lili's refusal to test, even though she could identify clearly some of the HIV positive symptoms she was experiencing, illustrates her level of denial. Lili's denial illustrates how people with or without awareness and knowledge about HIV use denial as a way of avoiding their own possible HIV positive status. As Meursing (1999) argues, denial can facilitate the progression of HIV/AIDS, as well as hindering HIV positive people from accessing care. It took being admitted to hospital for Lili to face her positive status. A similar level of denial was seen in the case of Godfrey (discussed above) who only discovered his status when he went for a medical examination when applying for a visa. Despite having seen an ex girlfriend die of HIV he still hoped and believed that he would be HIV negative.

Nolen (2007, p. 141) describes how, after her HIV diagnosis, Lili continued to live in denial:

> *The drugs soon made her well but she still didn't tell her friends what she had. Here was a lesson for the architects of Masa: ARVs could make a person well, but they did not end the shame of AIDS. Before long, Lili was taking her medication money her mother gave her and going back to Pretoria, blowing the cash on booze and parties. "I'm still waiting to die but I don't die. So I'm just going to have fun - I drank until I dropped".*

Lili's case illustrates the ways in which HIV can be denied, as well as the consequences of denial among HIV positive individuals. Maladaptive behaviours, like the abuse of alcohol, are associated with denial, which in turn causes the disease to progress. Van Dyk (2001) highlighted how people who are HIV positive are likely to go through periods of denial after being told their HIV status as a way of coping with the life threatening disease as well as reducing emotional distress. Ironson et al. (1994) demonstrated that denial of one's status is associated with maladaptive coping strategies such as alcohol abuse or engaging in risky health behaviours and a more rapid progression of the disease. These authors are of the opinion that denial is a defence mechanism that is "correlated with poorer mental health, greater distress and less ability to handle adverse situations well" (Ironson et al., 1994, p. 100). Other studies (e.g. Boland et al., 1999; Moore et al., 1999) also found that HIV infected women used denial and avoidance as coping mechanisms to deal with their HIV diagnosis.

4.3 Acceptance

4.3.1 Acceptance facilitates resilience

Nolen (2007, pp. 53-54) presents the case of Fred who demonstrated acceptance after his HIV diagnosis, which impacted positively on his wellbeing:

> *Up to now I feel very strong and healthy and I think something that creates better health with HIV/AIDS is your own mind- if you think all the time about AIDS, it will kill you fast. But my positive status doesn't trouble me and that's why I think I'm healthy.*

It is evident that Fred's ability to acknowledge his positive HIV diagnosis has led him to develop a positive attitude towards life, hence his self reported resilience. Plattner and Meiring (2006) remark that acceptance enables people to be in charge of their lives and to plan effectively for their future, hence enhancing their wellbeing. The above extract illustrates the association between acceptance of one's diagnosis and resilience: accepting his status created a positive attitude that enabled Peter to achieve emotional wellbeing.

4.4 Emotional responses

4.4.1 Anxiety experienced by HIV/AIDS affected orphans.

Nolen (2007, p. 35) depicts the case of AIDS orphans from Ethiopa, Joe and his14 year old sister, Sonia who was forced by her circumstances to adopt the role of an adult to take care of her younger brother after the loss of their parents due to HIV/AIDS:

> *But when It's coming to dusk, and she walks back home, when she takes the jerry can to the standpipe around the corner to buy water, puts a few pats of cow dung to burn in the brazier and boils a small pot of lentils- when she calls her brother Joe in from the street and chides him about his homework-then the illusion crumbles. After Joe falls asleep sprawled on to their one narrow bed and she has nudged him over to make room for her long arms and legs, then she lies in the dark and runs through the list. Is there money for rent? Is there money for their school fees? Is the money for lentils, more dung, and more water? And just where exactly is she going to find money for another sweater for Joe, because his wrists now dangle four inches below the cuffs of*

> *the one he has. "I shouldn't be worried about this," Sonia said to me. She spoke without bitterness or rancour simply to make clear that she knew what she had lost.*

In the above extract, Nolen (2007, p. 35) speaks about the emotionally stressful hardships and struggles that HIV orphans face on a daily basis, such as finance and lack of housing and sufficient food. This extract also illustrates the extraordinary constraints and worries that AIDS orphans encounter when having to switch from the role of child into that of an adult in order to provide care for their younger siblings. Mchombu and Mchombu (2007) observe that affected children who grow up without parents or appointed caregivers are likely to face challenges such as homelessness, malnutrition and/or poor health. The extract demonstrates that child headed families face enormous economic and emotional strain as a result of the massive responsibilities that they have to assume. Evans (2005, p. 125) remark that "child headed households are particularly vulnerable to extreme poverty and insecurity, resulting in lack of access to health care, education , property, livelihood and food security". The extract also reflects the difficult emotions these children have to cope with. Nolen (2007) describes a tone of bitterness and rancour when Sonia rightfully pointed out that she should not have to live the way she did. Basically, this extract reflects the anxiety experienced by older orphans about not being able to provide the basic needs required by their younger siblings, when they are obliged to switch into a parental role. Concerns about school fees, housing, and water can affect the wellbeing of older orphans, and this example demonstrates the burden that HIV orphans encounter, as well as the lack of resources in developing countries to assist HIV affected children.

4.4.2 Anxieties among HIV affected caregivers

Nolen (2007, p. 71) decribes the anxieties of Rebecca who was a caregiver to AIDS orphans:

> *In the natural order of things, these would be quiet days for Regina. She would sit in the shade of the large ream tree in her swept dirt yard in Malala in southern Zambia. She might sift a basket of beans in her lap, picking out the stones and twigs, and she might keep an eye on a pudgy baby just learning to totter. That should be peaceful, these days at the end of her life. Instead Rebecca works. She is up before the sun to start the fire for the maize porridge the children eat, and still up well after the sun has set, trying to comfort them with a story or hymn when they sit by the embers of the fire. And, although she is exhausted, she often lies awake long after the children have fallen asleep all crammed together in two round mud houses - there is much to occupy her mind. Instead of quiet twilight of old age that should be hers, Rebecca has work and worries and children.*

The extract above reflects the burden and challenges elderly caregivers caring for AIDS affected orphans face in their everyday lives. It is evident that Rebecca worried about how to provide care as well as basics such as food for her grandchildren to survive. The burden of care for Rebecca had a negative emotional impact such as sleep deprivation. A study in Uganda among HIV infected and affected elderly caregivers (Ssengonzi, 2007), found that caregivers were likely to experience negative economic, emotional and physical consequences as a result of the responsibilities of caring for HIV infected and affected individuals. The author emphasised that "the composition of the new household members, mainly young children, further accentuates the impact because of the children's inability to contribute to the household economy through gardening or assisting with chores such as fetching water or collecting firewood; yet, they need support and care" (Ssengonzi, 2007, p. 351). The demands of caring for the orphans impacted negatively on Rebecca's daily life as well as exacerbated the intensity of the care giving process which clearly had an effect on her emotional wellbeing. Moreover, the impact was aggravated by a lack of basic resources such as food. Rebecca's example also illustrates how the burden experienced by elderly caregivers due to HIV/AIDS is exacerbated by poverty. Rebecca also experienced physical strain from having to work from before sunrise until after sunset, further compromising her physical wellbeing.

4.4.3 Uncertainties and fears

Nolen (2007, p. 75) portrays the case of Rebecca who was worried, because of her age, about the future of the orphans for whom she was caring:

> *But that of course, was Rebecca's predominant worry. She is conscious of her age. What will happen if she dies? If Lolo gets sick or can't manage? She told me that her fear is that if the children are orphaned again, they will be separated, each one parceled out to a different family. No one she knows could be expected to take all thirteen. "I worry. I think the children shall suffer.......I am old now, but we thank God I can still manage.*

The extract above demonstrates the fear and uncertainty about the future of her grandchildren. Rebecca was conscious about her age and was distressed about who would be able to care for the children when she died. Her concerns are in line with a study by Mudavanhu (2008) which explored the psychological wellbeing of grandmothers in rural areas who were caring for their HIV/AIDS affected grandchildren. This Zimbabwean study found that most grandmothers expressed psychological distress or major concerns about who would care for the grandchildren when they themselves died. Nolen (2007) documents another concern voiced by Rebecca: the fear that when she died, her grandchildren would be separated and fostered by different families.

4.4.4 Hopelessness among HIV infected individuals.

Nolen (2007, p. 141) describes how Lili's HIV diagnosis affected her mental wellbeing.

> *Yes, she had Comnivir, but a bottle of pills didn't soothe the pain of being told she had a fatal disease at the age of thirty. Magic Johnson notwithstanding, she was infected with something she caught having sex. She quit her job, in Pretoria and lurked around her parent's house, feeling, she said, " like a black sheep, like I was cursed".*

It is apparent in the above extract that Lili's HIV diagnosis redefined her life, causing her to feel worthless and to express anxiety about the fact that she had HIV, even though she was taking ARVs. Not being able to work any longer because of HIV, and despite her youth, created emotional strain. A cross-sectional study (Olley, 2006) that explored psychological responses to their HIV status among 105 women in Cape Town found a link between having a psychological condition and having HIV. Major depression as well as post traumatic stress disorder were common among the participants. Olley, 2006, p. 214) also "found that within the participants there was a decrease in the three functional areas of work, family and social life ". The extract illustrates the emotional distress that infected individuals deal with in their everyday lives especially after a new diagnosis. One study (Smith et al., 1996) explored the quality of life among HIV symptomatic women and found that most participants experienced difficulties doing physical activities due to the disease which was likely to also cause emotional distress.

Nolen (2007, p. 131) also writes about the emotional struggles that Zack faced daily.

> *His viral load was critically high, and every week he contracted a new infection - bacterial, fungal, viral." I can't remember how many times I vomited. Diarrhoea was just a natural part of me". He had oral thrush, constant respiratory infections that left him gasping. The worst part was that the nausea and dizziness meant he could no longer concentrate well enough to read a single page. All his life his greatest joy had been reading, but now he could no longer get through an email. He conserved his limited shreds of concentration for TAC memos and speeches, the rest of the time he could barely get out of bed.*

This extract demonstrates not only the impact of the virus on Zack's physical health, but also how the illness redefines what one is and isn't able to do. Reading was one of the greatest joys of Zack's life, but the virus eventually limited his ability to read, something that he found extremely frustrating.

4.4.5 Uncertainties and fear among HIV infected individuals

Nolen (2007, p. 331) refers to Molly who was concerned about her children's future since she was HIV positive and extremely ill.

> *This was the idea that haunted Molly." I'm afraid for them", she said. "I don't want to leave them".*

It is evident that Molly (like Rebecca discussed above) was uncertain about her children's future. Brashers, Neidig, Reynolds and Haas (1998, p. 66) maintain that uncertainty is often worsened by the disease progression amongst people living with HIV/AIDS, and that "Uncertainty is a chronic and pervasive source of psychological distress for persons living with HIV". Other studies (e.g. McCain & Celia, 1995; Ramsey, 1990) found that there is a strong association between poor psychological wellbeing and HIV illness amongst HIV infected individuals. A sense of guilt for leaving her children behind was expressed by Molly. This extract also illustrates the cultural and social expectation/norm that women should care for and protect their children, adding to the strain experienced by HIV positive women, and impacting on their emotional wellbeing.

4.5 Resilience

Luthar, Cicchetti and Becker (2000, p. 543) define resilience as "a dynamic process encompassing positive adaptation within a context of significant adversity".

4.5.1 Resilience among HIV/AIDS orphans

Nolen (2007, p. 42) presents the case of Sonia and how she overcame adversity in her life.

> *And yet, in years since her mother died, she has kept herself and her brother Joe clean and fed and in school. In 2006, she stood nineteen of fifty two students in her grade 8 class; Joe is sixteen of twenty nine in grade 4.*

Sonia had committed herself to education as a way of surviving their current hardships and to ensure that their future would be brighter. Harms, Kizza, Sebunnya and Jack (2009) found that resilience as well as good mental health in AIDS orphans was associated with academic accomplishment and being optimistic about their future.

Nolen (2007, p. 43) notes how Sonia and Joe both demonstrated hope for a better future and a desire to change their circumstances:

> *When they walk down the main road on the way home from school, the children look in all shop windows. Joe tries to catch a few minutes of movies playing on TV screens, while Sonia likes to look at the clothes and the books, if they had more money, she said practically, she would spend it finding better housing and newer clothes and proper cooking pans. When I put the question to Joe, he answered instantly that he would pay for both of them to go to the best school in the city, and then he would buy trays and glasses, the things they need in the house. And perhaps, if there were lots of money, a television. When his sister was out of earshot, he confided, "I'd use it to take care of her'. And when Joe had gone out to run with his friends in the street, Sonia watched him through the doorway, her head against one slim fingered hand, and she said too, "if we had more, I would try to take care of him. I have to take care of him".*

Sonia and Joe had gathered the courage to dream and hope for a better future despite their inability to change their current conditions; however, they clearly had each other and a desire to care for each other. The hope and love for each other strengthened and developed their resilience. This extract also demonstrates the significance of support and love as a way to buffer the stress in time of adversity, thereby enhancing the psychological wellbeing of the individual.

4.5.2 Resilience among affected caregivers

Nolen (2007, p. 75) speaks about Rebecca who was a caregiver to her 15 grandchildren, and the ways she had adopted to overcome her hardships:

> *Rebecca was keeping the children fed and clothed - in itself something of a miracle - but she is worried a great deal about their spirits. "I try by all means to make the children happy, because if I look sad they will worry and wonder what is happening, so I must tell them jokes. In the evenings when we sit around the cooking fire, I tell them stories, I sing them songs. I wish them happiness".*

It is apparent from the above extract that Rebecca had demonstrated the ability to cope with negative circumstances and challenges as a caregiver by sharing jokes, songs and stories to ensure that her grandchildren were happy. The extract reflects how positive emotions such as happiness can facilitate resilience. Tugade, Fredrickson and Barrett (2004) assert that positive feelings shaped by humour and laughter can have a significant positive impact on the health of individuals. The social support that Rebecca provided for her grandchildren, as well as her close bonds with them had modified her adversity and her to adaptation to daily hardships, thus enhancing her own emotional wellbeing.

4.5.3 Resilience among infected individuals

The following extracts illustrate how some of the HIV infected participants demonstrated resilience towards the hardships and challenges of living with HIV.

Nolen (2007, p. 142) discusses the case of Lili and how she overcame the stress of being HIV positive when she was in hospital and extremely sick. Nolen describes Lili as someone who had a strong will and the ability to fight to regain her health:

> *Lili said when confronted with actual, imminent death, it didn't seem so appealing any more. And she was lucky to be young and strong enough that when she decided, with her unusual single- mindedness, that she wanted to live, her body could still fight back. She was filled with life".*

Nolen (2007, p. 173) writes about Ana who used her own HIV status to help other HIV infected people develop the courage to face being HIV positive. Like Lili, Ana showed a strength and determination that enabled her own health, but also allowed her to work with other HIV positive people:

> *... Ana got the job of nurse in charge of the Tisungane Clinic (the name means "coming together to help one another" in Chichewa) which was focused on getting people in to treatment. After a couple of months in the job, she nervously approached the young Canadian doctor running the project and confided that she herself had HIV. She was dreading a negative reaction, but instead he told her that she could be the best advertisement, and she took the role to her heart. One spring morning in 2005, I watched her get out of a shared mini-bus taxi, arriving for work, and lean back through the window, lecturing the driver even as he started to pull away. "There is no reason for you to die, since we've got medicine, 'she scolded him. "Look at me, I'm HIV positive, I'm on ARVs, I'm strong, I can take care of my children!" Smoothing her white skirt as she stepped in to the hospital, she shook her head. "These people, they tell me, 'You don't look like some of them'..." inside the clinic, the low wooden benches were filled with thin coughing, grim faced patients. Ana herded one group in to the room and in, her deep gruff voice, began their education. She told them how a person gets HIV: from sex and blood products and mother passing it to babies. She then told them how the virus works......*

Nolen (2007, p. 181 describes how Zack, having returned to life as his health improved, returned to activism and the fight for equality. Like Lili and Ana, Zack had determination and a fighting spirit:

> *But at the end of six months, he felt as well as he had ever had. Zack opened the windows turned off the VCR and decided he might as well go back to activism. There were great things to do in the new South Africa. He founded an organization called*

> *the National Coalition for Gay and Lesbian equality, and he fought for formal protection for gay rights in the new constitution. He also joined early efforts by people with HIV- in those days, mostly gay men fighting to end discrimination against those infected- and went to work for a fledgling organization called the AIDS Law Project.*

In the following extract Nolen (2007, p. 207) describes Lebo, an HIV positive twelve year old boy. Again he highlights a strength and determination that enabled Lebo to be focused on his future rather than on his illness:

> *Lebo himself had no interest in talking about AIDS. Instead, he was making plans for the future, although the subject presented something of a conundrum. When I asked what he wanted to do when he finished school, he paused for an uncharacteristic moment of reflection. "I want to work for police,' he began. "I want to catch thieves". He considered this and added, "Maybe I will be a doctor. And I think another thing I could do is be a prime minister. I'd use my salary and give all the people food. I'd help them plant maize and pumpkin and watermelon and then sell it". His short term agenda is much clearer. I will live and will go to school".*

The above extracts reflect how all the participants adapted to their situations or stress by ensuring that they had the ability to make positive outcomes out of their experiences of living with HIV/AIDS. Although they had successfully adapted to their difficult situations by taking a positive approach to life, all of them demonstrated resilience differently within their unique contexts. For instance, Lili demonstrated positive self efficacy in order to overcome her adversity. Resilience was shown by the strong desire to fulfil her purpose in life. For Ana and Zack, resilience was displayed by making a difference through educating others about the disease and trying to create awareness. Both of them demonstrated that they had a belief in their capacity to make a difference around the issue of HIV/AIDS. Lebo displayed a strong sense of confidence in a brighter future. Resilience was reflected in his desire to reach his career goals and most importantly, his hope to live. The extracts above illustrate the strength and resilience of many people with HIV. Lastly, these extracts reflect ways and means by which HIV infected individuals can demonstrate resilience within different contexts to enhance their wellbeing.

4.6 Experiences of death

4.6.1 Responsibilities above grief

Nolen (2007, p. 72) describes how Rebecca experienced multiple losses due to HIV/AIDS:

> *In 1998, one of her daughters died in Lusaka, and she took a rickety shared taxi to the city. "I went and assessed the situation. Their father did not have much left for him. According to our tradition, as the grandmother you are responsible. You cannot disregard your grandchildren. "So she brought those children to Malala. The second daughter-in-law died, and the two children were sent to Rebecca. Then her third daughter, Lilly, lost her husband and came home bringing her surviving child and two orphans from another daughter. Before long there were a dozen children, in city clothes rapidly starting to fray, and at the age of 74 Rebecca's days of sitting in the shadow were over.*

In the above extract, Nolen (2007) focuses on the responsibilities that Rebecca was left with after multiple deaths within her family. Cook and Oltjenbruns [2003], cited in Mudavanhu et al. (2008, p. 79) argue that "researchers have largely ignored the grief process that grandparents go through". The extract above illustrates that grief among elderly HIV affected caregivers is often overshadowed by the massive responsibilities they have to fulfil, such as caring for the surviving orphans. Furthermore, this illustrates the need for interventions to help caregivers to address their grief issues as a way to promote their wellbeing.

Another participant that Nolen (2007, p. 36) writes about is Sonia, a 14 year old orphan who had lost both parents due to HIV:

> *"Now there is no one for me to ask for advice. I think about my mother when I'm worrying about what to do to provide for my brother. If my mother were around I wouldn't have the responsibility of my brother and we would have her love and focus just on our education".*

Since her mother's death Sonia had become responsible for providing for her brother.

Nolen (2007, p. 201) also describes the responsibilities Peter and Jane were left with when their daughter-in-law died:

> *'She died that evening, after gently reminding her small son that he must mind his grandparents. Peter and Jane now had Leon and his older brother, Neo to take care of, so they took in a lodger, and Peter invested their savings in a tractor that he could hire out for plowing around Khola.*

Lastly, Nolen (2007, p. 276) presents the case of Tom who was left to look after his daughter after he had lost his wife due to HIV:

> *Tom barely remembers the last few months, left suddenly alone with the daughter and a demanding ministry, his dreams in England abandoned.*

It is interesting to note that in the above extracts Nolen (2007) does not reflect directly on the grief of the participants, but highlights their responsibilities. This suggests that the immediate needs of the children left behind are of primary importance for all the participants, requiring immediate attention.

4.6.2 Grief verses poverty

Demmer (2006, p. 104) found that among professional caregivers assisting clients with HIV related grief, what was significant was that "poverty overshadows lives of clients with grief being of less concern". Nolen (2007, p. 42) discusses the case of the orphans, Sonia and her brother and the additional stressors that hinder their mourning:

> *Even a heavy bolt cannot ease her worries. "The thing I fear the most is housing. Right now I pay 70 birr - tomorrow it might be 90 birr or 100". As Addis struggle to care for more orphans, it has less money to give to Sonia. She worries the next time she approaches them, for school fees or help with food there will be nothing left. "We have to live on streets. We will have no option. "That's the worry I have all the time".*

The extract above illustrates the constant worries and realities that AIDS orphans face. It is interesting to note that while Nolen (2007) commented on Sonia's experience of death, Sonia highlighted the material worries that she was left with as a result of being an orphan. Although there is no direct evidence of it, these orphans may be at risk of complicated grief as they are not able to deal with the emotional stressors associated with the death of their loved ones.

Another participant presented by Nolen (2007, p. 73) is Rebecca who had to deal with poverty while watching her daughter die:

> *Rebecca led me inside this one and introduced me to one of her youngest daughters, Jenny, who was then exactly my age, thirty-two. She was lying on the floor on a fresh grass mat, and dying. Every hour or two her toddler daughter crept up to the door and peered around it to where her mother lay. Sometimes Jenny gave her a little wave. Rebecca has a constant struggle to care for this brood, ranging from a fifteen-year old boy to several grubby babies. Kim, the only other adult in the family, is fifty-one and has grandchildren of her own and could reasonably expect to be retiring. Instead she has moved back home to help her mother. "It's difficult - the only way I manage is*

> *what little I get, I give them," Rebecca said. "Even if it's not very nice food - as long as it helps them live.*

Although Nolen (2007) does directly mention it, seeing her daughter die must have been a very difficult emotional experience for Rebecca. However, what is highlighted is the financial difficulties imposed on the family because of her dying daughter's inability to work. It appears that the financial demands overshadow Rebecca's emotional reaction to witnessing her youngest daughter dying of AIDS.

4.7 Interpersonal Factors

4.7.1 Disclosure

4.7.1.1 Disclosure vs. rejection

According to Nolen (2007), most of the participants underwent disturbing situations after disclosing their HIV status due to the stigma and discrimination that society holds towards those infected and affected by HIV/AIDS. Nolen (2007, p. 330) describes the case of Molly and Ben (a married couple) living with AIDS, and how their family reacted to their disclosure:

> *His devotion stood in sharp contrast to the attitude of Molly's own family members, who shunned her after she told them she had AIDS. "When Molly's parents heard about it, they refused to take care of her or to even come and see her" Ben said. "They say I am the one who brought sickness, and are blaming me". Not a single member of her family had contacted them since she had been bedridden, and when Molly's sons tried to visit their grandparents, they were chased away from the home.*

The impact of public disclosure for Godfrey is described by Nolen (2007, p. 236):

> *While Godfrey knows his decision to go public had a huge impact on people, he sometimes regrets it - he still gets hassled nearly every time he orders a beer.*

Nolen (2007, p. 334) discusses the case of Iran who faced discrimination once he had disclosed to his work colleagues:

> *So he told a few of his colleagues. But they did not adapt. Soon management made the work environment too hostile for him to stay.*

It is evident from the above extracts that Molly, Godfrey and Iran suffered negative consequences following their HIV/AIDS disclosure, contributing to added stress in dealing with this life threatening illness. What is most interesting about the extracts is that each participant disclosed in a different context but they experienced similar negative responses. Kalichman et al. (2003, p. 316) recommend that "HIV disclosure demands careful consideration because potential for adverse social consequences including rejection, abandonment and physical assault" can occur. Godfrey's disclosure created added stress in his life because the negative reaction continued even when ordered a beer. This reflects the stigma that society holds about people living with HIV/AIDS. Lastly, Iran's situation of disclosing led to the loss of his job. Skinner and Mfecane (2004, p. 161) remark that "in all relationships discrimination counteracts trust" and therefore leaves people with AIDS isolated as they deal with the disease. Ncama (2007) found that environmental support enhanced the wellbeing of HIV infected individuals. The extracts above reflect the harsh reality that despite needing social support many people with HIV/AIDS receive harsh discrimination and rejection.

4.7.1.2 Positive consequences following disclosure of one's status

Although the extracts presented above reveal the negatives consequences following disclosure, some participants experienced positive consequences after disclosure. The following extracts illustrate some of the positive experiences.

Nolen (2007, p. 228-229) writes about Godfrey and the reaction he received following his disclosure:

> *Soon he was the country's AIDS outreach effort, a campaign of one. He found it strangely comforting, despite the staring crowds and their probing questions. "I was feeling as if the burden was removed, the sense of worthlessness. One of the things that happen to you when you are HIV positive is that you lose all self esteem". Godfrey didn't feel so bad when he spoke before crowds. And by standing up in front of them, he shattered the myth that a person infected would be visibly wasted and ill.*

It is interesting to note that Godfrey experienced both negative and positive consequences to disclosing his status. It was noted above that he sometimes regretted having made his status public because of the attention that it attracted. However, in the above extract Nolen (2007) notes that Godfrey found his disclosure comforting.

Nolen (2007, p. 364) describes the circumstances that led Thabo to disclose his status to his girlfriend, as well as her reaction:

> *His most pressing concern was for his close friend Salina whom he'd dated a couple of years. They had had a condom break a couple of times, and he was consumed with fear that he might have infected her with HIV. So he went to see her that night, told her the news. She was, as always, staunchly supportive, much more concerned for him than for her health.*

The response to Lili's disclosure is presented by Nolen (2007, p. 142):

> *...And at the centre she was given rudimentary training in public speaking and she began to do small talks in workplaces, telling people how she was living healthy on ARVs. She loved the attention, and how the people drank up what she had said. She was a college graduate who was publicly HIV positive, and made them listen.*

The above extracts illustrate not only the different situations in which the participants disclosed, but also the commonalities among them. Godfrey and Lilly both found comfort and gained confidence by disclosing. Both of them disclosed as a way to challenge the myths that people have towards HIV/AIDS, and to create awareness. In Godfrey's case, disclosing his status was followed by a positive reaction from the public, which enhanced his self esteem. The extracts reflect the significance of disclosing to others as a way of facilitating acceptance of one's status. For Thabo, disclosing his status to his girlfriend led him to receive social support and eased his concern that he might have infected her. Studies have indicated that disclosure of one's HIV status can be associated with positive consequences such as social support which enhances the wellbeing of the individual (e.g. Bor, 2001; Cusick & Rhodes, 1999). Ncama (2007, p. 392) contends that "disclosure of HIV status is an essential aspect in prevention, care, treatment and support for people living with HIV/AIDS".

As observed above, for one person the experience of disclosure can be both positive and negative, as in the case of Godfrey. This highlights the complexity of disclosure (Klitzman et al., 2004).

4.8 Social support

4.8.1 Family support

Nolen (2007, p. 82) discusses the social support that Martha received from her family when she was in the later stage of AIDS and how it enhanced her medication adherence:

> *Staff at JCRC told Martha's family that there was little point in them buying the drugs; a person simply could not recover from all that ailed Martha. But her mother, Jane, quickly sold her land to buy the first few months' worth of medication, and sold all household furnishings; other relatives lent money. Jane and Mimi stayed by Martha's bed every moment, desperate to see the drugs have some effect. It took months, but just as they were about to give up, Martha began to recognize them, make sense, to want to sit and eat. By August she remembered that she had children. Soon she was out of hospital, learning to walk and talk again. Her father would sit and count her regimen tablets and watch the clock, making sure she took each one at the correct time.*

In the following extract, Nolen (2007, p. 85) records what Martha said about the social support she received from family and friends:

> *"The reason I survived was from support from my family and my friends, the second was that Uganda was open. Drugs are third. But love and support - those are first".*

Lebo was an HIV orphan cared for by his grandparents (Nolen, 2007, p. 201):

> *On nights when he was very ill, he would creep in to his grandparents' bed and wake Jane up, asking her to sing that Hymn. Jane in turn woke Paul and together they would sing to the wheezing boy.*

Nolen (2007, p. 301) portrays the case of Ana who contacted HIV through a polygamous marriage, and the support she received from the other wives after their husband's death:

> *There was something sweet about all three of them and the warm family life they had built out of a situation they could have never chosen. It was clear that Ana had only a few weeks to live, and Anoka and Grace were keeping close to her.*

The extracts presented above show how the social support that participants received from their families had a positive impact on their wellbeing. In Martha's case her family made many sacrifices to get the drugs she needed.". The first extract reveals how family social support enhanced Martha's ability to adhere to treatment and promoted Martha's wellbeing and health. Ncama et al. (2009) found a strong link between social support and adherence to ARVs and concluded that individuals who were granted social support were likely to adhere to, and be consistent with, treatment. Kalichman et al. (2003, p. 315) are of the opinion that "social support is an important aspect of psychological adjustment for people living with HIV infection". Martha, Lebo and Ana illustrate how social support can help people who are HIV positive adjust to and accept their diagnosis and thus promote their wellbeing. These participants' experiences also suggest that being infected with HIV need not necessarily result in stress and that, if provided with sufficient support from families, friends, works groups or social networks in which an individual is embedded, a person with HIV can, in fact, accept their diagnosis and deal with it in positive ways.

4.9 Institutional factors

4.9.1 Prejudice

4.9.1.1 Prejudice towards HIV/AIDS infected people in hospitals.

Nolen (2007, p. 81) discusses the case of Martha, a Ugandan doctor who was admitted to hospital because she was extremely ill with HIV/AIDS in South Africa.

> *In June, she was admitted to hospital in the small coastal city of East London. There the nurses told her, "Go home to Uganda and take the disease with you". They would not feed or bathe her: they stuffed her full of Valium so that she would die quietly and not distract them from their work. "They were waiting for me to die as soon as possible".*

The above extract reflects the hostility that Martha encountered within the hospital environment where the staff made it extremely difficult for her to regain her strength and to get medical care. This highlights the challenges and realities that people with HIV/AIDS face in hospitals. Similarly, in Nigeria, Reis, Heisler, Amowitz, Moreland, Mafeni and Anyamele (2005) found that 44% of health care professionals displayed discriminatory attitudes and practices towards HIV infected inpatients, and 9% refused to care for or treat people with

HIV/AIDS, showing the kind of hostility towards people with HIV within the hospital environment.

4.9.1.2 Prejudice towards HIV infected people in the workplace and universities.

Nolen (2007) describes the cases of two individuals who were discriminated against in their work environments. The extracts presented below illustrate the prejudice that Iran and Godfrey experienced.

Nolen (2007, p. 227) writes about the situation that forced Godfrey to test for HIV:

> *His visa application involved a routine medical, including an HIV test.*

According to Nolen (2007, p. 334), Iran experienced prejudice at work after disclosing his HIV status to management:

> *Soon management made the work environment too hostile for him to stay.*

Both Godfrey and Iran experienced negative consequences within their work environments. When Godfrey tested positive for HIV, he was no longer eligible to pursue his scholarship, and prejudice in the work environment resulted in Iran losing his job.

4.9.1.3 Prejudice towards HIV infected people in churches.

Nolen (2007, p. 277) describes the case of Peter who was a priest and teacher. The following extract illustrates how he was treated after he disclosed his HIV status to the church community:

> *He told his students, who were for the most part, encouraging, and then began to tell - and warn - the wider church community. "It was very risky," he said. It's still risky. There are still people who are uneasy about my message - 'why is he talking all these stories? Doesn't he care about the image of the church?"*

The above extract reflects the norms and expectations that authorities in the church are expected to fulfil. Moreover, HIV is often associated with immoral behaviour. Preau et al. (2007) contend that in certain instances religion plays a major role in preventing people living with HIV from disclosing their status due to fear of being stigmatized. Carr and Gramlings (2004, p. 38) notes that "Providing educational programs for churches, corporations, and civic groups would raise knowledge levels, alleviate unrealistic fears, and diminish the level of stigma associated with HIV/AIDS".

4.10 Community factors

4.10.1 Stigma

4.10.1. Stigma limits life of HIV infected individuals.

Nolen (2007, p. 141) speaks about Lili who "self stigmatized" as a result of her HIV diagnosis:

> *Treatment hadn't ended stigma. It had barely dented it. If any of the high-priced consultants who drew up Botswana's AIDS plan had talked to Lili, they might have seen this coming. Yes, she had her Combivir, but a bottle of pills didn't soothe the pain of being told she had a fatal illness at the age of thirty. Magic Johnson notwithstanding, she was infected with something, something she couldn't get rid of,*

> *something she caught having sex. She quit her job in Pretoria and lurked around her parents' house, feeling "like a black sheep, like I was cursed". Every time she swallowed a tablet, she thought about AIDS, about how she was marked, stained and spoiled.*

The above extract illustrates how stigma associated with HIV has a negative impact on well being. The stigma was so overwhelming for Lili that it even changed the way she perceived herself. For her, the diagnosis redefined who she was and overshadowed not only her accomplishments but everything she had been prior to her diagnosis. Lili perceived herself as worthless. Nolen (2007) writes that Lili felt "like a black sheep". Mfecane (2004) asserts that stigma and discrimination attached to HIV influences the maintenance of the HIV epidemic among people living with HIV/AIDS. Simbayi et al., 2007) that explored the link between stigma and psychological wellbeing among HIV infected individuals confirmed a link showing that stigma was associated with psychological conditions such as depression and posttraumatic stress disorder in HIV positive individuals. Furthermore, Naidoo et al. (2007), in a study conducted in five African countries (Lesotho, Malawi, South Africa, Swaziland and Tanzania) confirmed that self stigmatization was likely to be common among PLHIV in rural areas rather than in urban areas, affecting their psychological and physical wellbeing. The difference between the rural and urban groups was ascribed to urban areas consisting of larger social networks where gossip is most common, also people from urban areas are at advantage to access better resources such as health care access as opposed to rural groups and lastly, it was pointed out that people in urban areas have higher level of literacy, that is, awareness as opposed to rural groups.

Nolen (2007, p. 370) describes Thabo who was discriminated against by staff after disclosing his HIV status:

> *Because he was doing well on the drugs, he felt more comfortable talking about the fact that he was infected, less like a freak who might waste away and die any moment. At the bookstore staff meeting, he read a poem he was working on about living with HIV. A couple of women wept, he encouraged them to ask questions but no one did. But after that if he took a day off, everyone scrutinized him for signs of illness when he went back to work.*

The above extract shows that Thabo was aware of the strong stigma towards people living with HIV, and co-workers' negative emotions towards him. Skinner and Mfecane 2004, cited in Naidoo et al. (2007, p. 18) remark that "A major role that stigma plays is that it separates people, creating a feeling of superiority for those who are not affected by the stigmatising trait and establishing a feeling of shame in or towards the group who is stigmatised".

4.11 Gender Inequality

4.11.1 Fear of economic exploitation

Nolen (2007, p. 299) writes about Martha who depended on her husband for financial support, giving him power to dominate in their relationship:

> *Ben bought Martha treasures from the city: a mattress, sateen bedspread, new lengths of bright print capulana, the cotton wraps that Mozambican women wear as skirts and shawls for their babies. He built a sturdy brick house with glass windows and roof*

> *made in tin sheeting, the only house like that in the village. Then in 1985, when Martha had a couple of small children, Ben came home with something else: a new wife, a girl of just twelve. Martha was chagrined: suddenly Ben was putting another brick building in the yard, and she had to share the kitchen with the girl, a child really whose plump body her husband clearly relished. But when he went back to the mines, she and the girl-bride, Anoka, learned to live together.*

The above extract reflects how women are entrenched in a cultural norm that limits them from expressing their views around their husbands. Culture and financial power that favour the views of males prevents Martha from challenging her husband's opinions; as a result, she is submissive towards her husband and forced to comply with her husband's rules. Women who are rooted in a patriarchal culture face such challenges on a daily basis. Jewkes, Levin and Kekana (2003, p. 127) maintain that "Economically vulnerable women are highly dependent on men's financial contributions and are thus less likely to succeed in negotiating protection and less likely to leave relationships that they perceive to be risky". Similarly, Brandt (2008) argues that women who are economically vulnerable are at higher risk of contracting HIV because of the pressure to provide for their children. This extract reflects how economic dependency can jeopardize women's ability to be assertive or voice their opinions in relationships, thus increasing the spread of HIV/AIDS.

Nolen (2007, p. 300) speaks about Martha an HIV positive infected women from polygamous marriage.

> *In 1993 came wife number three –Gracinda Invane a Twenty three and beautiful high cheek bones and big eyes, one again Martha ,now relegated to the position of tired oldest wife, shuffled her possessions around the home stead's and made room for another family . 'I couldn't say anything ". She said. "He was happy having two wives, and I had to accept it"*

It is apparent from the above extract, that women who are still entrenched in cultural norms are obliged to be submissive towards their husbands due to norms set by society, these norms hinders them from expressing their opinions regarding their husband's decisions. Further, this illustrates the position which men have over women in households thus impacting negatively on women's wellbeing. Moreover it is evident that women are vulnerable to HIV due to the inequality amongst different genders. Women such as Martha are at a greater risk of contracting HIV due to power dynamics among men and women especially among traditional individuals. Baingana,Thomas and Comblain (2005, p.4) [this ref not in ref list] argue that "social and economic powerlessness and low status relative to that of men/boys is the root cause of women's and girls' greater vulnerability to HIV infection, their disadvantaged position in coping with it and their greater suffering from its effects."

4.11.2 Difficulty negotiating safer sex with the partner.

Nolen (2007) discusses how some of the female participants encountered difficulties in negotiating safer sexual practices with their partners/husbands. Martha expressed fear in talking about AIDS or negotiating sexual practices with her husband because she feared rejection and violence as a consequence of her attempt (Nolen, 2007, p. 300):

> *"I never talked to Ben about AIDS. It would be very frightening talking to him about that, 'Martha told me with a shudder. What, I inquired would have happened if you had asked him to wear a condom? "He would have beaten me", Martha replied, astonished that I even had to ask; beaten her and almost certainly chased her from the home.*

After learning of her HIV positive status, Ana attempted to negotiate safer sexual methods with her husband (Nolen, 2007, p. 171):

> *So Ana went home and told John that if they were going to have sex again, they would have to use a condom. He flatly rejected the idea, sneering that he would just go to "bar girls" instead. "Why would I bother with an old cockroach like you?" Ana flinched and recounted his words, she knew and she will tell anyone who asks, that he had infected her. "I was a virgin when we married, so he couldn't blame me".*

Martha is an example of women who are still rooted in cultural norms, whereby women are expected to be passive in sexual interactions. Martha was unable to even talk to her partner about safer sex. The extract reflects how gender inequality plays a role in relationships, as well as the fear that women have towards making decisions in relationships due to the power that men have over women. Martha speaks about the risk of being beaten if she initiated the negotiation of safer sex, illustrating how women are in danger of contracting HIV/AIDS because of the power dynamics between men and women. In contrast, Ana's case is an illustration of the challenges faced by some women who confront sexual issues with their partners. Ana's effort to negotiate safer sexual practices due to her HIV diagnosis led to her experiencing verbal abuse and rejection. These examples indicate how women are physically as well as socially vulnerable to HIV/AIDS in a variety of contexts, with such inequality making it difficult to combat the pandemic.

4.12 Poverty

4.12.1 Financial challenges among HIV/AIDS orphans.

Nolen (2007, p. 42) describes how two orphans (Yan and Sonia) stay alive:

> *Yan sometimes earns a few birr shining shoes - although more than once he has been robbed by older boys who steal his money and the brushes and polishes for which he saved for months. Sonia earns a bit, too: she's good with hair, and the neighbours will give her three or four birr (40 cents) for afternoon braiding.*

Child headed families face major challenges and emotional strain in order to survive. Sonia and Yan's circumstances forced them to earn money from odd jobs in order to stay alive. Donald and Clacherty (2005) explored the risks and strengths of child-headed families as well as adult-headed families affected by HIV/AIDS and living in communities affected by poverty in South Africa. They found that child-headed families were more likely to be engaging in informal jobs such as washing people's clothes, braiding, and selling cigarettes, which was their only source of income.

4.12.2 Financial challenges among HIV/AIDS caregivers

Poverty forced many sacrifices resulting in major negative consequences for the physical state (blood pressure) of Rebecca (an elderly caregiver), and for the emotional wellbeing of both herself and the AIDS affected orphans that she cared for (Nolen, 2007, p. 73):

> *... "It's difficult - the only way I manage is the little I get, I give them," Rebecca said. "Even if it's not very nice food- as long as it helps them to live. The biggest problem is that I have to till the land, and I have no animals to help me plant the maize field." Her back aches, and it pains her to hoe and plough, but she has no cash to hire labourers from the village and must rely on the work of the older children. Her worries have given her high blood pressure. After she slowly lowered herself to the ground, to sit and rest for a minute or two, she rubbed her swollen calves with gnarled hands. The children were dust smeared and grimy, wearing short trousers made out of feed sacks. It is a source of some shame for Rebecca, who knows that her grandchildren are worse off than her own children were. The newest child in the house that day was an infant a few weeks old, born to a fourteen year old granddaughter. Rebecca said, looking pained and embarrassed, that she was surprised by the pregnancy, but then it isn't uncommon for orphaned village girls to have sex with older men for cash or food. She wants the children to go to school, but in Zambia it costs 8,850 kwacha per year per child or about $2.50 - a huge burden. On the holidays and between terms, the older children go out to hoe the fields of better off farmers near town to earn kwacha; thus far, it had been enough to keep them enrolled for another term. Sometimes there is a bit left over for a new shirt or a pair of shoes that are worn only to school and church and otherwise kept stored away*

Rebecca was faced with financial constraints that diminished her quality of life. Studies have shown that poor economic conditions make coping difficult for affected caregivers to care for orphans (e.g. Howard, Phillips, Matinhure, Goodman, McCurdy & Johnson, 2006; Lili, Lin & Sun, 2007). Howard et al. (2006, p. 7) note that "Many caregivers especially the elderly are impoverished , ill, tired and emotionally drained from having cared for and buried relatives and taken in their orphans". They conclude that educational incentives and community support structures are necessary to assist caregivers and strengthen families.

4.12.3 Poverty among HIV infected individuals.

Molly and her husband Ben from Zimbabwe were both HIV positive and struggling to buy ARVs which they could not afford (Nolen, 2007, p. 322):

> *Molly, at thirty- two, was dying from AIDS, and the drugs to keep her alive, to make her well again , were for sale at the pharmacy just down the road. Molly and Ben, who was thirty five, knew about ARVs and they knew how it worked. And not long ago, they could have bought them - when they were doing okay, by the standards of Southern Africa: both were high school graduates, and Ben had a full-time job as a security guard, while Molly used to make enough to cover household expenses as a market trader, before she got too sick to stand at the stall. They knew about the drugs, and they should have been able to buy them. Instead, Molly lay dying, and Ben wondered how long it would be before it was him.*

The extract above illustrates how poverty can compromise the health of an individual. In this case Molly was extremely ill and dying from AIDS, her health condition being exacerbated by the couple's inability to afford medication (ARVs) to make her well. Moreover, lack of resources such as money to buy medication added a burden of worry to Ben because it raised the concern of whether he would be able to live long enough to care for his dying wife, since he was also HIV positive. "While the consequences of AIDS have been felt across all population groups, the disease is most prevalent among impoverished people with fewer resources for coping" (World Bank, 2004, p.3). Poverty affects HIV affected caregivers; HIV orphans as well as HIV infected individuals. Booysen and Bachmann (2002) contend that HIV/AIDS is very common among impoverished people thus increasing the trend of poverty, and therefore future interventions should deal with the socio-economic impact of the disease.

4.13 Public policy

4.13.1 Policy influence amongst infected individuals

Nolen (2007, p. 139) writes about Lili an HIV positive woman from Botswana, the influence of the government response to HIV/AIDS, as well as the impact it had on Lili's health:

> *"This was a radical notion: that the treatment that could keep people with AIDS alive was available in Botswana. Available, that is to people who could afford to pay $350 a month. Presented with the bottle of ARVs, Lili agreed to test. When it came back positive, her mother immediately bought the first month's supply of drugs.*

Lili benefited from the approach of the Botswana government towards the fight against HIV/AIDS since her mother could afford the drugs to improve her health status.

Zack was a South African-based activist, whose work on HIV included the broader struggle for treatment to be made accessible for people living with HIV/AIDS in South Africa (Nolen, 2007, p. 193):

> *A few days later, Zack marched with thousands of other TAC members to the site of South Africa's first-ever national AIDS conference. Many key members of the government were inside. Zack faced the crowd. "I decided to take my medicines", he said. The response was a deafening roar. "I'm not going to die because they want us to die." The crowd broke into songs and dancing. It wasn't just that Zack would live, there was a public benefit in having such a high-profile person take the "poisonous" drugs and get well. "It is high time that South Africans see that these drugs are lifesavers", said Dr Kgosi, chair of the South African Medical Association. Yet in the media, Zack's decision to take the pills was characterized as the end of "unsuccessful efforts to force the government to give its people the medicine." That was a bitter spin to have to live with. But four days later, the South African cabinet, in a stunning reversal, announced that it would begin to take steps to make ARVs available to the public clinics.*

The above extract indicates how Zack's courage, struggle and hard work in persuading the government to make ARVs accessible were a success. Although he was HIV positive, activism kept him strong because he was able to help others as well as develop resilience and become a hero. Mchombu and Mchombu (2007) identify various policy measures that have informed the response to HIV in Africa: control programs such as awareness and prevention campaigns have been adopted to fight the pandemic, with an evident decrease in infected people; some policies such as ARV policies adopted in Africa have prolonged the lives of HIV infected people and instilled hope. Mchombu and Mchombu (2007) advise, however, that although governments have adopted policies to respond to the pandemic, major challenges such as lack of sufficient resources still remain.

The above extracts illustrate how policies can have a positive influence on the health of people with HIV especially in poorly resourced countries. Zack's activism demonstrates the importance of collectivism in addressing health concerns, which led to the government effort to make treatment accessible saving the lives of many HIV infected people.

4.14 ARVs give hope to people with HIV/AIDS.

Nolen (2007) discusses some of the participants who almost lost their lives and suffered from numerous infections which created misery in their lives. She documents how the participants presented below used ARVs, resulting in an improvement in their health and a return of hope.

Lili overcame her negative emotions as a result of the impact of ARVs (Nolen, 2007, p. 141-142):

> *Within weeks of stopping the pills, she was sick again: her hair was falling out in clumps, her skin was peeling off. She got sick, her family had to keep her on diapers,*

and she decided she couldn't wait any longer for death that was dragging its feet. 'I thought, I'm going to suffer and going to die" - I just wanted to bring that day". She made a concoction of bleach, fabric softener, detergent and all the pills in the house, and drank it down. She was in a coma for three days. She awoke in hospital to the news that she had pneumonia, stomach tumors, tuberculosis and Kaposi's sarcoma. Her CD4 count was 8. Doctors told her family that this horrifying array of illnesses would almost finish the job she started with her poisonous homemade cocktail. Yet, Lili beat the cancer, and the tuberculosis. She got over pneumonia and her lesions healed. "There is no one who went through what she went through and is still standing" Avo, her doctor, told me. 'I was lucky to facilitate her will to live. She's my inspiration". Lili said that when confronted with actual, imminent death, it didn't seeming appealing any more. And she was just lucky to be young and strong enough that when she decided, with her usual-mindedness, that she wanted to live, her body could still fight back. She was filled with the sense that her life was spared for a purpose. 'I still have to do something in life'. Soon she was out of hospital and back on ARVs taking them religiously this time. Her CD4 count slowly climbed.

Lili's health worsened when she stopped taking the pills. She experienced feelings of despair and hopeleneness and she attempted suicide and was confronted with imminent death due to multiple infections. Studies have demonstrated an association between mental disorders and HIV (e.g. Brandt, 2008; Mijch, Burgess, Judd, Grech, Komiti, Hoy, Loyd, Gibbie & Street, 2006; Olley, 2006), with the most common disorder being major depression. In a study in Chicago . They found that both lack of interest in activities and depression were more common among people with HIV compared to those without HIV. Hughes and Kleespies

(2001) argue that there is a strong link between people with HIV and suicide which is often associated with psychological, mental and physical dysfunction.

When Lili stopped taking the ARVs her physical and emotional condition deteriorated. Gilbert and Walker (2009) note that adherence to ARVs among people who are HIV positive can reverse their serious health status and bring them back from the brink of death. Similarly, according to the Report on the global AIDS epidemic (2008, p. 132), "the impact of antiretroviral drugs on the management of HIV infection has been startling, with improvements in health proving to be far more marked and enduring than anticipated when combination antiretroviral therapy first emerged in the mid-1990s".

Zack explains how ARVs brought his life back and how he managed to do things that he could not previously manage due to his illness (Nolen, 2007, p. 194):

> *...One day in early September he held in his palm his first Triomune, the generic combination pill. He felt a cold tickle of trepidation - after all those years of listening to the health minister rant about poison, he had momentary qualms. "I thought what if I turn green or something?" he later recalled with a laugh. Or what if he was one of that small number of people for whom antiretrovirals simply don't work. He swallowed. The strike was done. Five days later, he was on his hands and knees scrubbing his kitchen floor. 'I hadn't cleaned my own home in four years!" he said giddy with the memory. "And more importantly within a week I had read an eight-hundred-page book - a history of the Spanish Civil War. And all my energy flowed*

> *back. I was capable of holding a thought, speaking, engaging, being nice. And within two weeks I was almost a whole human being.*

Clearly, Zack was nervous about taking ARVs because the then South African government had convinced him that they were poisonous. The ARVs, however, had a positive impact on his health, instilling a sense of hope and enabling him to get his strength back so that he could do the chores he had not been able to do when he was sick. Zack's example also reflects the complexities and challenges of managing treatment when governments oppose it. Gilbert and Walker (2009, p. 1128) found that "ARVs are transforming the experience of living with HIV/AIDS for many respondents", and indicated that the provision of treatment amongst HIV positive individuals facilitated their ability to manage HIV like any chronic diseases thus enhancing their wellbeing. For Zack, ARV's restored his energy and hope when he could perform simple, pleasurable activities such as reading which he had been unable to do when experiencing multiple infections due to HIV.

Twelve year old Lebo, who was HIV positive, was always sick and was being cared for by his grandmother, Janine because his parents had died of AIDS. ARVs restored Lebo's childhood as well as hope for his future (Nolen, 2007, p. 206):

> …"*He had made it to twelve, against outrageous odds, and it was high time he got a little help. Pillay broke the news to Janine that …had AIDS, and the grandmother assumes this means he would die. But Pillay told her that, just as she had hoped for so long, there was a new tablet, and something could be done. Janine had never heard of*

> *anyone getting treated for AIDS; when people in Khola get sick, they lay in darkened rooms at home until they died. But this whip-thin, fast talking doctor was counting tablets to her, telling her which ones ...would have to take each morning and which at night. Yet as she sent the grandmother and the boy away, Pillay wondered to herself if even drugs would do it. She feared his immune system was too worn out. A month later, back in Kolo for clinic day, she looked out the window and saw.....charging up the hill. His face was fuller; he stayed awake, he laughed more - the lucky chuckle that is such a surprise coming from his little boy's body. When he stepped on the scale he had tipped over the 25 kilogram mark; he ran through the clinic like a prize fighter, pumping his arms in the air and accepting hugs from the staff.*

Due to HIV/AIDS, Lebo had been sick his entire childhood, hindering his ability to develop like other healthy children. His story illustrates the challenges and struggles that HIV infected children face; it also points to the growing demands for governments to provide sufficient health resources to people infected with HIV so that they might be reinvigorated with the hope to live. Lebo's health improved not only because he had a supportive family, but also because he was put on ARVs. Gilbert and Walker (2009) assert that the provision of ARVs to people with HIV has removed the perception of doctors simply preparing people for death, but has brought hope to them.

These extracts demonstrate how a wider contextual factor such as policy can both enhance and positively shape the health the wellbeing of an individual. Nolen (2003, p. 322) maintains that "all over Africa there are people with HIV who, because of cost or logistics, cannot get access to the medicines that will keep them alive".

CHAPTER FIVE: CONCLUSION

The aim of this study was to adopt an ecological framework to understand the experiences of fourteen HIV infected and affected individuals. According to McLeroy et al. (1988), this model looks at the experiences of an individual in a holistic manner by taking into account their subjective experiences, as well as the wider social environment that influences and shapes their experiences of health and illness. Various factors, including intrapersonal, interpersonal, institutional, community and public policy factors contribute towards people's experiences of health and illness, and these different levels of analysis are interdependent or interrelated, contributing to the health or illness of an individual (McLeroy et al., 1988). My study looked at how these various factors come together to impact on the way in which individuals experience being HIV positive, or being affected by HIV/AIDS. In this concluding chapter, I summarize the main findings of the analysis and make some concluding comments on these findings in relation to the ecological conceptual framework that informed the analysis of the stories of the fourteen HIV infected and affected individuals.

5.1 Intrapersonal factors that impacted in the stories of the participants

McLeroy et al. (1988) argue that intrapersonal factors can have either a negative or positive influence in addressing health related concerns among individuals. They state that the ability of an individual to experience good health depends on that individual's ability to change their extraordinary circumstances; for instance, an individual who demonstrates the desire to fulfill their purpose irrespective of their adverse health conditions is more likely to experience good health as compared to individuals who are emotionally distressed as a result of their difficult health conditions (McLeroy et al., 1988).

The findings of this study suggested that some of the intrapersonal factors which were evident in shaping the health or illness of the HIV infected and affected participants included factors such as knowledge, denial, acceptance, a range of emotional responses, and resilience towards being HIV positive. With regard to knowledge, most participants lacked knowledge about HIV/AIDS, making them reluctant to test even though some of them were presenting with symptoms. The analysis found that those who knew their HIV diagnosis disclosed their status to their sexual partners to avoid infecting others. Other participants who had knowledge regarding their HIV positive status associated it with death and loss of hope in the future. Some participants were in denial about their own HIV status despite knowing the symptoms. Denial tended to be used as a coping mechanism, but had a negative influence in that it hindered them from accessing medical care thus affecting their health. The findings further illustrated that acceptance was beneficial for some of the HIV positive participants as it facilitated resilience in them.

McLeroy et al. (1988) contends that it is important to acknowledge the relationship of intrapersonal qualities with the environment which can shaping people's experience of health or illness. Most of the infected individuals experienced feelings of worry, uncertainty and hopelessness with regard to their HIV diagnosis. Some participants such as Lili, Ana and Lebo adapted to their stressful situations by demonstrating resilience. Lili demonstrated resilience with positive self efficacy in order to overcome her adversity and a strong desire to fulfil her purpose in life. For Ana, resilience was demonstrated by making a difference through educating others about the disease and trying to create awareness. Lebo displayed resilience through a strong sense of confidence in a brighter future and his desire to reach his career goals and, mostly importantly, his hope to live. The HIV affected orphans believed that education was the key to a better life for them, and educational opportunities helped them to overcome their adversity. HIV affected caregivers overcame their adversity by forming close bonds with their grandchildren, and the HIV positive participants demonstrated resilience by trying to create awareness about their HIV diagnosis.

5.2 Interpersonal factors that influenced the stories of the participants

McLeroy et al. (1988, p. 356) suggest that "interpersonal relationships with family members, friends, neighbors, and contacts at work are sources of influence in the health related behaviors of individuals", and that these interpersonal factors play a significant role in shaping an individual's wellbeing as well as the ability of an individual to cope with life stressors.

My study found that some participants were ostracized, rejected or abandoned by their families and colleagues as a result of disclosing their HIV diagnosis; other participants, however, experienced positive consequences, which facilitated acceptance and social support thus enhancing their physical and psychological well being. Family support also influenced the wellbeing of some HIV infected individuals because it enhanced their ability to adhere to their treatment and enabled resilience. For example, Martha regained resilience through social support from friends and families, enhancing her ability to adhere to her medication and treatment. My analysis indicated the importance of social support from friends and families for people who are HIV positive. My findings concur with the view of McLeroy et al. (1988) that states that social relationships influence how an individual copes with their life stressors. Participants such as Molly, Iran and Godfrey who suffered negative consequences following their HIV/AIDS disclosure experienced additional stress in dealing with their life threatening illness. What is most interesting about the extracts is that the participants disclosed in three different contexts but they experienced similar negative experiences after disclosure. For instance, Molly and Ben were shunned, rejected, ostracized and abandoned by family members.

5.3 Organizational factors that influenced the experiences of the participants

McLeroy et al. (1988, p. 359) assert that "organizations' structures and processes can have a substantial influence on the health and health related behaviors of individuals" since they form a significant social identity for individuals. Organizations can also facilitate or encourage behavior change or "provide the individuals with HIV/AIDS the chance to build social support for behavioral change. This can be achieved by organizations rendering training, creating empowerment and offering incentives to individuals to promote their wellbeing. However, a hostile organizational environment could negatively influence the health of some individuals making it more difficult for them to recover from their illness.

The opinion of McLeroy et al. (1988) coincides with my findings; hostile environments within organizations did have a negative impact on the health of some of the individuals in the stories who experienced prejudice within different organizational contexts such as hospitals, workplaces and churches. These negative attitudes made it extremely difficult for them to regain their strength, get medical care and to keep their jobs. For instance, Martha was discriminated against within the hospital setting when she was admitted, which made it extremely difficult for her to cope, adjust and recover from her condition. Iran and Godfrey were also discriminated against within their work environments. For Godfrey, his diagnosis led to him losing his job, and for Iran his diagnosis rendered him ineligible to take up a scholarship that he had won.

Peter, a priest, was discriminated against in the church environment when he disclosed his HIV positive status. His congregation assumed that he had engaged in taboo or immoral behavior making his adjustment to his HIV positive status difficult. These responses show the stigma that people from different organizational contexts hold towards people with HIV.

5.4 Community factors that influenced the experiences of the participants

McLeroy et al. (1988, p. 366) maintain that "an important component of community includes mediating structures; these structures are repositories and important influences on the larger community's norms and values, individuals beliefs and attitudes and a variety of health related behaviours". These structures also connect an individual to the wider social environment (McLeroy et al., 1998). People with HIV/AIDS are discriminated against, usually have little control over how their community operates and limited access to political and power structures in their communities, and experience the most ill-health (McLeroy et al., 1998). Nelson and Prilleltensky (2005) contend that one of the principles of the ecological model is adaptation, which suggests that people must cope and adapt to changes in communities and societies. In my findings, people had to adapt to and cope with extreme poverty while faced with HIV/AIDS.

The analysis suggests that among the infected and affected HIV participants, some of the community factors that influenced their experiences of health and illness included poverty, stigma, gender inequality, and difficulty negotiating safe sex with partners. For example, Lili and Thabo experienced intense stigma due to their HIV diagnosis, which severely limited their lives. The stigma was so overwhelming for Lili that it even changed the way she perceived herself. The diagnosis redefined who she was and also overshadowed her accomplishments and everything she had been prior to her diagnosis.

Gender inequality was a major contributor to the spread of HIV among some participants. Martha, who was in a polygamous marriage, was not able to negotiate safer sex with her husband because she was financially dependent on him and expected to be submissive towards him. Another participant, Ana, who attempted to negotiate safer sex with her partner was verbally abused, negatively influencing her wellbeing. This indicates the power dynamics between the genders in society and how gender inequality can shape the health of an individual.

Among both affected and infected participants, poverty played a role in worsening their experience of HIV. Financial constraints made survival a major challenge for participants. For instance, earning money from odd jobs was the only way for HIV affected orphans to survive. Rebecca, an HIV affected caregiver, was faced with the financial strain of raising her grandchildren which diminished her own quality of life as well as aggravating her physical problems. The HIV infected couple, Molly and Ben were living in extreme poverty which made it difficult for them to access better health facilities and treatment.

5.5 Policy factors that influenced the experiences of participants living or affected with HIV

ARVs played a major role in giving hope to people living with HIV, impacting positively on their wellbeing. Policies drawn up to fight or address HIV/AIDS tend to focus on prevention and awareness campaigns, or on providing treatment (ARVs) to HIV positive individuals (Mchombu & Mchombu, 2007). However, in Africa, challenges such as limited funding serve to reduce or restrict access to ARVs or treatment for people who are HIV positive (Mchombu

& Mchombu, 2007). Hardon (2005) also argued that since Africa is a poorly resourced continent, ARVs were considered to be very expensive in most countries.

Public policy impacted on some of the individuals in the stories. For instance, Zack was initially nervous about taking ARVs because the government in his country had over the years convinced him that they were poisonous. However, he challenged his government by taking the ARVs, which enabled him to get his strength back and to do the chores he had not been able to do when he was sick. The medication brought hope to Zack and others like Lili and Lebo. Lili, having overcome her negative emotions about living with HIV, took her ARVs, resulting in enhanced physical and psychological wellbeing. And lastly, for Lebo, who had been born with HIV and had always been sick, ARVs restored his health.

5.6 How the different levels of analysis are interdependent

According to Nelson & Prilleltensky (2005, p. 71) the ecological principle of interdependence "asserts that the different parts of an eco-system are interconnected and that changes in any one part of the system will have ripple effects that impact on other parts of the system". For instance, intrapersonal factors such as emotional distress can be linked to community factors such as poverty or stigma.

The principle of interdependence was clear in my analysis of the stories of individuals infected and affected by HIV. Some of the affected HIV orphans who had undertaken a parental role expressed concern about not being able to provide for the basic needs of their younger siblings. This example shows how poverty and lack of resources impacts on and directly affects the individual at the intrapersonal and interpersonal levels, and how the different levels interact and are interdependent. Similarly, HIV affected caregivers also worried about how they would provide their grandchildren with basics such as food. This, again, reflects how a community factor such as poverty can affect the individual at the intrapersonal level. One HIV positive woman expressed guilt and fear around leaving her children behind when she died. This woman's concerns reflect a cultural and social expectation that women should take primary responsibility for the care and protection of their children. In this example gendered expectations at a community level have a direct impact on the emotional stress (intrapersonal level) of this woman who has to worry about the future of these children.

Some HIV affected orphans, such as Yan and Sonia, found encouragement from being committed to education, which became a way of surviving their current hardships. This example illustrates how wider contextual factors such as education can foster resilience at an individual level. On the other hand, some of the affected caregivers such as Rebecca have adapted to their hardships by forming close bonds and supporting their affected grandchildren. This demonstrates how an interpersonal factor impacts on the development of resilience at the intrapersonal level. The findings also established that amongst some HIV infected and affected individuals, social support (interpersonal factor) impacted positively on their personal wellbeing.

The findings further illustrated the importance of interpersonal processes such as disclosure. Participants such as Lili, Thabo and Peter experienced stigma and discrimination when they disclosed to their families, organizations or social networks, showing the link between the organizational, interpersonal and, in turn, the individual level. Furthermore, for Thabo and Peter the stigma was so intense that it impacted on them at an interpersonal level. The different levels, therefore, interacted in shaping the participants' experiences. For participants who received a positive reaction to their diagnosis and received family support, there was a positive impact on their wellbeing. The above example demonstrates how the different levels, organizational, interpersonal and intrapersonal, work together to make HIV a manageable experience for some people.

Some community factors such as stigma had a negative impact on the well being of some HIV infected participants. For instance, for one participant, the experience of stigma from the community regarding her HIV diagnosis was so overwhelming that it even changed the way she perceived herself. In a sense, her diagnosis redefined who she was as well overshadowed her accomplishments and everything she had been prior to her diagnosis. This demonstrates how a community factor such as stigma can influence the individual level of experience in a negative way. In addition, some HIV positive participants experienced difficulty in negotiating safer sex with their partners. This demonstrates how an interpersonal level factor like gender makes the individual level of risk higher by making the negotiation of safer sex at an interpersonal level difficult. For instance, Martha was unable to negotiate safer sex with her husband because she feared that she would be financially disadvantaged. Ana attempted to negotiate safer sex with her partner, but was verbally abused for voicing her concern. Lastly, the study established that public policy such as ARV distribution by the government can enhance the lives of HIV positive participants by giving them hope and improving their health.

From a preliminary review it is clear that most research on HIV/AIDS tends to examine separate aspects of HIV/AIDS like stigma, treatment and social support, but few studies investigate it from an integrated perspective. In other words, it does not explore the way in which all the different 'levels of influence' come together to impact on the way in which individuals experience their illness. It is argued that the ecological framework is a useful theoretical framework that can be used to inform research on people's experiences of HIV/AIDS, as it takes in consideration both the social context as well as intrapersonal qualities to understand the health of people living with HIV/AIDS.

Research on issues related to HIV/AIDS has tended to focus more on the intrapersonal factors of the individual while disregarding the macro factors that shape health and illness. My study adopted an ecological model to understand the health of people with HIV/AIDS taking into account the social context of an individual, and focusing on the multiple levels of analysis rather than focusing on only one level. The ecological model places people in social systems and seeks to consider individuals in a holistic manner within the social contexts in which they are embedded to understand health and behaviour. In addressing health concerns, the ecological model "challenges individualistic interpretations to problems and strives to reframe problems, taking power and social context into account" (Murray et al. 2004, p. 329).

In conclusion, this study found that adopting an ecological framework to understand the experiences of HIV infected and affected individuals is useful because this model looks at the experiences of an individual in a holistic manner by taking into account their subjective experiences as well as the wider social environment that influences and shapes their experiences of health and illness

Future studies should examine more closely the influence of social contexts in which individuals are embedded in order to understand the health as well as experiences of HIV/AIDS infected and affected individuals. My findings highlight the importance of considering the social environment not only when designing interventions to fight HIV/AIDS but also in research to understand the health and illness of HIV infected/affected individuals.

The limitations of the study are that the data (stories) was already collected. Future studies could make use of primary data collected from direct interviews as this would enable the researcher to make a much more in depth analysis and enable them to consult with the participants on an ongoing basis. It is also suggested that future studies could narrow their focus, for example, it would be interesting to focus exclusively on the experiences of elderly caregivers or children or males.

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