

CHAPTER 1

INTRODUCTION

1. 1. INTRODUCTION

The World Health Organization WHO (2005) and the United Nations on HIV/AIDS (UNAIDS, 2006) estimate that AIDS has killed more than 25 million people since it was first diagnosed. UNAIDS (2006) furthermore deducts that in 2005, AIDS claimed about 2.4 to 3.3 million people of which 57000 were children, a third of these deaths are occurring in Sub-Saharan Africa, impacting on economic growth.

According to the Center for HIV Information (CHI) (2006), Sub-Saharan Africa has just over 10% of the world's population, but it is home to almost 64% of all infections, with an estimated 21.6 million to 27.4 million people living with HIV infection. Sub-Saharan Africa has the world's highest HIV prevalence and faces the greatest demographic impact. In the worst affected countries of Eastern and Southern Africa, the probability of a 15 years old dying before reaching the age of 60 has risen dramatically. In some countries up to 60% of today's 15-years olds will not reach their 60th birthday (Timeaeus & Jassen, cited in UNAIDS, 2004).

Southern Africa remains the most heavily affected area within sub-Saharan Africa. In a number of countries, in regions, the spread of HIV within the general population has exceeded what was previously envisaged. In Botswana and Swaziland, the high infection rate is still increasing with estimated national HIV prevalence rates as high as 33, 4% in Swaziland (UNAIDS, 2006).

According to the Health Systems Trust (HST) (2004) South Africa is among the most inequitable countries in the world. South Africa represents a highly symbolic case because of its ability to reflect the social and economic inequalities that exists at the global level. Current estimates indicate that South Africa has the largest number of PLWA.

The Nelson Mandela/ Human Sciences Research Council (HSRC) study of HIV/AIDS (Shisana & Simbayi, 2002) which was a household study looking at a proportional cross-section of society reported that from 8428 people tested nationally, 11.4% were found to be HIV positive (also see Rehle & Shisana, 2003). It was found that South Africans aged 2 years and older were living with HIV/AIDS in 2002. It was found that the HIV prevalence was highest in Africans at 12.9%, followed by Whites at 6.2%, Coloureds at 6.1% and Indians with the lowest prevalence of 1.6%. It was also found that females had a much higher HIV prevalence (12%) than males (9.5%). These results also showed that HIV prevalence among adults aged 15-49 years was 15.6% with 17.7% in women and 12.8% in men in this age group. Rehle and Shisana (2003) pointed out that among Africans aged 15-49 years a prevalence of 18.4% was found it is acknowledged that the epidemic was highest in people living in urban informal settlements (21.3%) compared to those living in urban formal settlements (12.1%) or those in rural areas (8.7%).

A follow up study by Shisana et al. (2005) showed a notable difference from the previous survey in 2002. They found that the survey in 2005 found a higher HIV/AIDS prevalence among youth aged 15-24 years (10.3% vs. 9.3%) and a similar prevalence in adults 25 years older (15.6% vs. 15.5%). HIV/AIDS prevalence in the 15-49 age groups was 16.2% in 2005 and 15.6% in 2002. Results show that the prevalence in children aged 2-9 years is high. Boys aged 2-4 years had a prevalence of 4.9% and 5.3% among female children. Among boys aged 5-9 years the prevalence is 4.2% and 4.8% among girls.

These prevalence rates portray HIV/AIDS as a significant problem in South Africa and consequently of the social implications that it brings with it to individuals, households, communities and on society as a whole. As described by Freeman (2003), the diagnosis of an HIV infection can be traumatic for the infected person and his or her family members. Together with this diagnosis comes the fear of rejection, isolation, and stigma, loss of financial and social status. Families often do not know how to respond as well as how to cope with the condition at hand and many live in constant uncertainty about the effects of the pandemic on the rest of the family and the rest of the community. Although, people respond in many different ways to the diagnosis, the most common response is

that of uncertainty (Avert, 2006; Kelly 2001). In a study conducted by Kelly (2001) on an HIV/AIDS prevention, care and support program in the Eastern Cape, it was found that some people are reluctant to share a meal prepared by someone who is HIV positive. He continues to say that in order for people living with HIV/AIDS to be able to cope with their status, they need psychological support and guidance from health care professionals, family members and the community at large.

The United States Agency for International Development (USAID) (2001) state that South Africa faces significant challenges in addressing the severe impact of a mature and generalized HIV/AIDS epidemic. Within the past 10 years. HIV infection rates in antenatal clinics grew from less than one percent in 1990 to nearly 25 percent in 2001 South Africa's epidemic also shows no evidence of slowing. Between 4, 9 million and 6.1 million people in the country were living with HIV in 2005. Almost one in three pregnant women at ante-natal clinics were found to be HIV infected in 2004 and since then there has been an increase in HIV prevalence. The UNAIDS (2006) assumes that the main factors responsible for high prevalence of HIV/AIDS in South Africa are poverty and social instability that result in family disruption, mobility linked to migratory labour systems, high levels of sexually transmitted diseases, low status of women, sexual violence and ineffective leadership (UNAIDS, 2006).

1.2. RATIONALE FOR THE STUDY

According to the Antivirus Emergency Response Team (AVERT) (2006), the high prevalence of HIV and AIDS in South Africa poses a major challenge. An estimated 6 million South Africans are expected to die from AIDS-related diseases over the next 10 years. Based on the Department of Health's national ante-natal survey which was released in 2006, involving anonymous testing of pregnant woman at state health care facilities, an estimated 4.5 million South Africans were living with HIV in the year 2005.

Jackson (2002) believes that from a mental health perspective, the context in which an illness spreads and thrives must be taken into consideration. Loomis and Beegle (1997)

state that rural areas are isolated from the rest of the world and yet they have high HIV/AIDS rates. The families in rural areas have rigid boundaries; they thus make their own rules and subcultures, which are non-normative. They further point out that most studies on rural areas seem to focus on the impact of HIV and AIDS on rural areas, and yet the rural areas are impacted negatively by the HIV/AIDS pandemic with the highest HIV/AIDS prevalence rate (Loomis & Beegle, 1997). The impact of HIV/AIDS is being felt most acutely in households, among families and within communities. Young people and children are actually watching their hopes and dreams crumble as parents and caregivers die of AIDS. According to Jackson (2002), family functioning is associated with a variety of positive and negative psychological outcomes in HIV positive populations, but the family plays a major role. How the family reacts to the stress of having an HIV positive family member may influence the psychological, emotional and behavioural adjustment of the infected person (Jackson, 2002).

The imbalance of power sharing between men and women also has a great impact on how HIV/AIDS is perceived. In some communities women are still oppressed. If they are HIV infected the blame will be on them, whereas most women, especially those from rural areas contract it from their husbands. HIV/AIDS is well known to be affecting mostly vulnerable members of the society who are women, children and elderly people in many ways (AVERT, 2006). There is a series of assumptions and idealizations about the nature of the identity that individuals should assume through their life-cycles as a child, as a teenager or youth, as an adult and as an elderly person. However, the way in which these identities are actually played out in all stages of the lifespan; they are fundamentally shaped by economic and social imperatives which make possible and influence the realization of a number of issues within in the society (Silverman, 1993).

Silverman (1993) further gives an example that the social belief remains that children should live a life of innocence, nurtured, untouched by responsibility, but in fact many children have battled with the responsibilities that poverty brings upon them and which result in responsibilities well beyond those expected from children. HIV/AIDS, which is leaving many children without parents, is bringing these idealizations into questions. Due

to HIV/AIDS the role of adults as productive and reproductive members of society is also being challenged by early deaths. This brings the potential contribution that these adults may contribute to production and reproduction into question. The belief of old age as a stage of rest and reaping of fruits of productivity is also challenged (Heath, 2000).

This study therefore investigated the psychological and the social impact HIV and AIDS poses on family members. Sometimes the exercise of power within the family is brutal and violent, sometimes it is exercised with love and care to socialize and nurture. Understanding the impact of HIV/AIDS on this does not make an easy generalization (Barolsky, 2003). This study targets families in rural areas through perceptions of health care professionals and social services professionals. This research will therefore, contribute to strengthening interventions that address some of the issues such as cultural and traditional practices and views of black rural communities affected by this epidemic through the help of these professionals.

1.3. AIM OF THE STUDY

The main aim of this study was to investigate the psychosocial impact of HIV/AIDS on rural families as perceived by health care and social services professionals.

1.3.1. Research Questions:

This study attempted to answer the following questions.

- How do health and social services professionals perceive the impact of HIV/AIDS on rural families?
- In what ways has HIV/AIDS impacted on the structures of rural families?
- How the impact of HIV/AIDS has changed the cultural definition of a family?
- Which kind of coping strategies have rural families adopted in responding to the psychological and social impact of HIV/AIDS?

1.4. LAYOUT OF THE REST OF THE REPORT

This research report consists of five chapters. The first chapter introduces the concept of HIV/AIDS and its psychosocial impact on families. Chapter 2 provides different theoretical frameworks that explain the impact of HIV/AIDS. Hence the models of choice to explain the psychosocial impact of HIV and AIDS in families is the family system's theory, psychodynamic theory and Eric Erickson's psychosocial theory in attempting to explore how HIV/AIDS cause change in families, but most of these studies were individualistic. Therefore this study aims at exploring specifically the psychosocial impact of HIV/ AIDS on families, especially in rural areas, how this has changed a typical definition of a rural family as well as the roles that each individual member of the family plays and also how the family manages the change in structure, in times of stress.

Chapter 3 presents methodological issues for the study. Objectives behind the employed approach are provided, including discussion of participants, the research method, research instrument and the procedure. The chapter also discusses the analysis method of data employed as well as the ethical considerations during data collection. Chapter 4 discusses the results of the study as well as the responses of perceptions of health care and social services professionals on the psychosocial impact of HIV/AIDS on rural areas. Themes emanating from these findings are comprehensively discussed linking them with the literature reviewed. The final chapter, which is Chapter 5 provides summary of the findings of the study and discusses the limitations. It also highlights meanings postulated by these professionals, attached to this findings and their implications for HIV/AIDS' psychosocial interventions. The chapter also provides recommendations for further research.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. INTRODUCTION

While recent scientific efforts have resulted in a series of discoveries and advances in understanding and controlling the virus that causes AIDS, the progression has had limited impact on the majority of HIV infected people and populations living in developing countries (Lyons, 2000). HIV infections affect all dimensions of a person's life, physical, psychological and social well being (WHO, 2005). There are also complex psychological and social issues that impact on a family's ability to cope with HIV and AIDS condition. The psychological and social aspects of HIV and AIDS infections are devastating to children, adolescents, women and their families (Tomaszeski, 2001).

According to Bell (1989) HIV/AIDS not only attacks individuals but attacks family systems as well. Until the last decade HIV/AIDS has been perceived primarily as a health problem, and be contained by effective health education programmes. Coombe (2000) points out that the deadly virus has not been contained and continues to spread widely. He also suggests that it consequently has a profound adverse impact on communities and institutions. Tomaszeski (2001) further mentions that HIV/AIDS is a chronic illness that forces individuals and their families to cope with uncertain progression of the disease, complicated medication issues and the grief related to the loss of health and possibly the loss of family members.

According to the Health Resources and Services Administration (HRSA) (2003), although most HIV/AIDS cases continue to be in cities, more cases are being seen in rural areas. Multiple obstacles may hinder the development of HIV/AIDS care programmes, however, inattention to HIV/AIDS may be caused by underreporting of cases.

This literature reviewed in this chapter will attempt to conceptualize some of the concepts like family, psychosocial, and rural areas and also explore how families are impacted by the HIV/AIDS pandemic, looking specifically on the psychosocial impact. Section two of this chapter discusses the theoretical framework which will underpin the understanding of the dynamics of the impact of HIV/AIDS on families.

2.2. PSYCHOSOCIAL IMPACT

2.2.1. Operational Definition: Psychosocial

Sternberg (1998) defines psychosocial as pertaining to how social factors interact with personality throughout the life span. According to Freeman (2003) HIV condition is not only a medical issue, but also a psychosocial one as well. Infection and its progression present individuals with a broad range of personal experiences to negotiate constant adaptation. Individuals infected with HIV have to develop new patterns of coping as the disease progresses. Freeman (2003) further indicates that at the same time; the individual's condition may trigger a variety of reactions from others such as family members, significant others, co-workers and professionals. Kubler-Ross (1997) mentions various medical stages that people with HIV/AIDS undergo and these stages include the following: Acute and primary; early stage Asymptotic; Early to Middle Stage Symptomatic; Advanced HIV, Late Stage. Parallel with the medical stages outlined above, HIV disease has several psychosocial stages which are outlined below.

2.3. Psychosocial Responses to HIV Diagnosis

PLWHA must deal with strong emotional issues. Each of these stages includes a variety of emotional responses such as fear, loss, grief, anger, depression, feelings of dependency and hope. The emotional responses of HIV/AIDS will be discussed below.

2.3.1 Fear

According to Kubler-Ross (1997), fear is among one of the feelings that affected people as well as infected experience. Fear and shame may prevent the person living with AIDS from confiding in others and gaining support. They may also be reluctant to seek help. Fear can arise in the infected person from the unpredictable nature of the disease. Fear can also arise in others who live with the person, they may pull away because of irrational fears of contagion or fear of the person's death, therefore leaving the PLWHA with a deep sense of isolation and loss (Green & McCreaner, 1996).

2.3.2. Loss

HIV brings about losses and sadness is one of the emotions of experiencing too many losses. PLWHA may have to deal with loss of the deceased lovers, children and friends while at the same time mourning their own fate. Many repeated losses can cause complicated bereavement (Shisana & Simbayi, 2002).

Other losses may include loss of family, friends, co-workers, ability to do things they used to, weights, appetite and physical attractiveness, social role, income, and employment. Tomaszewski (2001) is of the view that individuals with HIV/AIDS may be overwhelmed by the loss of a number of family members as well as coping with their own diagnosis. He further states that loss of parents and changes in caregivers interfere with the mastery of developmental milestones and coping abilities of children and adolescents.

2.3.3. Grief

According to Kubler Ross (1997), grief is the subjective feeling precipitated by the death of a loved one. The expression of grief encompasses a wide range of emotions, depending on cultural norms and expectations (e.g., some cultures encourage an intense display of emotions, whereas others expect the opposite) and on the circumstances of the loss (e.g., sudden unexpected death versus death that is clearly anticipated). Grief work is a complex psychological process of working through the pain of having lost someone. van Dyk (2005) identifies three stages of grieving which are (1) how did the person die?

What caused the death? Was the death sudden, gradual, painful, and easy (2) what did the person mean to you? Were they friends, a partner, co-worker, parent, and child? (3) How will you learn to live without the person? What do you need to do to continue with life?

2.3.4. Guilt

Guilt and self blame for having contracted HIV and for also infected others are often expressed by an HIV positive person .These feelings of guilt may be associated with the person's conflicts about their and sexuality and also having to tell their family and friends that they are infected (van Dyk, 2005). He further mentions that there is guilt associated with how the person's loved about the sadness they may inflict in them.

2.3.5. Denial

Hedge (1990) claims that after an HIV/AIDS infected person has been told of their status, they may appear dazed at first and then may refuse to believe their diagnosis, they may deny that anything is wrong with them. Some people never pass beyond this stage and may go from one doctor to another until they find one who supports their position. The degree to which denial is adaptive or maladaptive appears to depend on whether a patient continues to obtain treatment even while denying the prognosis. However, counsellors should confront this denial if it causes destructive behaviour such as refusing appropriate medical care (Doka, 1997; van Dyk, 2005).

2.3.6. Anger

HIV infected persons become frustrated, irritable and angry at being ill. They commonly ask "why me"? They become angry at God, their fate, a friend or a family member or they may even blame themselves (Straus, 1975). According to van Dyke (2005), people with HIV disease may blame themselves for getting infected as well as blaming the family for not being able to do anything, not showing empathy and not being able to find a cure. They may also blame the society for lack of support and lack of understanding as well as being angry at medical institutions for failing to find a cure Doka, 1997re. The fluctuating nature of HIV disease and interference with the health care delivery system

can cause frustration and anger. The need to stay in control can sometimes produce such behaviour as quarrelling, arguing, complaining or being demanding.

2.3.7. Anxiety

van Dyk (2005) further states that the chronic uncertainty associated with the progress of HIV infection often invokes feelings of anxiety. PLWA often experience anxiety because of the prognosis of the illness, the risk of infection with other diseases, the risk of infecting loved ones with HIV/AIDS as well as the fear of dying in pain without dignity. Kubler-Ross (1997) also mentions that there exists inability to change the situation and the consequences of HIV infection, uncertainty about how to keep as healthy as possible in the future, fears about the ability of loved ones and family to cope, worries about availability of appropriate medical treatment, a loss of privacy and concerns about confidentiality, their declining ability to function efficiently and their loss of physical and financial dependence.

2.3.8. Low self-esteem

Self-esteem is a concept that includes a person's sense of self, their competence and their acceptability to others. It encompasses their internal self-scheme based on their past experiences of success or failure and their interpersonal experience of acceptance or rejection (Germann, 2004). The self-esteem of HIV positive people is often severely impacted. Rejection by colleagues, friends and loved ones can cause loss of confidence and loss of one's sense of social identity, leading to feelings of reduced self-worth. The inability to continue in a career or to participate in social, sexual and loving relationships also diminishes the client's self esteem. The physical consequences of HIV infection such as physical deterioration and the loss of strength and bodily control contribute even more to lowering of self-esteem (van-Dyk, 2005).

2.3.9. Depression

According to van Dyk (2005), HIV positive people often experience depression. The individual may show clinical signs such as withdrawal, psychomotor retardation, sleep disturbances, hopelessness and possibly suicidal ideation. The depression may be a

reaction to the effects of the illness on their lives, or it may be anticipation of the loss of life that will eventually occur (Heckman, 1997). The following factors cause the increase of depression: the absence of cure and the resulting feeling of powerlessness, knowing others who have died of AIDS, the loss of personal control over ones' life and the self blame and feelings of guilt (van Dyk, 2005).

2.3.10. Hope

Individuals with HIV/AIDS, maintaining hope is not merely a virtue, but a primary task. It appears that people actually live longer when they can hope for and plan future activities, achievements and relationships (Kubler-Ross, 1997). Hope sustains them through the inevitable 'bad days' and increase the capacity to appreciate periods of good health. Feelings of hope fluctuate daily and sources of hope differ from person to person. Hope can be strengthened by maintaining spiritual practices and meditation. Hope is sustained by maintaining employment and relationships with co-workers, becoming involved in activist groups, cultivating social and family ties and finding meaning in new roles or new experiences. The most important factor in maintaining hope is active participation in decision making. Any intervention that enables a person with HIV/AIDS to feel in greater control of their health care and activities strengthen their feelings of hope (Kubler-Ross, 1997; van Dyk, 2005).

2.3.11. Socio-economic issues

There are various factors that have contributed to the impact of the HIV/AIDS epidemic in South Africa. The disruption of family and communal living that resulted from apartheid and migrant labour has had a major impact on the structure of families. Families were forced to move to rural areas and were separated making it difficult for them to access support (UNAIDS, 2006). Traditional black communities have experienced a breakdown in social cohesion. This breakdown has contributed to the rapid spread of AIDS.

South Africa has one of the fastest growing AIDS epidemics in the world, with up to 2,000 people being infected by the Human immune –deficiency virus daily. While there

are limits to AIDS prevalence in the overall population, it is estimated that 1 in 8 South Africans are now HIV positive. The rapid spread of HIV/AIDS has enormous socio-economic implications for both the general population and South Africa as a whole (Heath, 2000).

The World Bank (1990) cited in May (2000) defines poverty as the inability to attain a minimal standard of living measured in terms of basic consumption needs or income required to satisfy them. Poverty is thus characterized by the inability of individuals, households or entire communities to command sufficient resources to satisfy their basic needs. The authors of the World Development Report draw a 'poverty line' that separates the 'poor' from the 'non-poor' based on the expenditure necessary to buy a minimum standard of nutrition and other necessities. This expenditure varies between countries and therefore country-specific poverty lines have to be developed in order to measure poverty in an easily tractable way. May (2000) further states that the convention adopted by the Poverty and Inequality Report (1998) is to use a poverty line that is measured in monetary terms. Thus poverty line does not necessarily reflect actual expenditures, but rather the monetary value of consumption. Recognizing that poverty lines will differ over time and space and the deciding where to draw poverty line is ultimately something that needs further exploration (Joffe, 2001).

May (2000) further mention that the practice adopted by the Rural Development Programme (RDP) study has been followed. 'Poor' has been defined as the poorest 40% of households and 'ultra-poor' as the poorest 20% of households. According to these definitions, households that expend less than R352, 53 per month equivalent are regarded as poor, households that expend less than R193, 77 per adult equivalent are regarded as ultra-poor. Just fewer than 50% of the population live in the poorest 40% of households and are thus classified as poor. Similarly, 27% of the population live in the poorest 20% of households and are thus classified as ultra poor.

According to the World Vision International (2005) poverty does not cause HIV/AIDS. However, it definitely creates a socio-economic context where people are more vulnerable to infection and where the effects of an infection will be even more

devastating. When people live under sub-human conditions, with few comforts and limited prospects for the future, it means to them that in few years they may die from the virus, which they do not understand (Jackson, 2002).

Lyons (2000) states that poverty is clearly a factor in the spread and impact of HIV/AIDS. The struggle to survive everyday overshadows attention and concern about a virus that does not demonstrate any immediate harm. HIV/AIDS is a distant threat until it has a visible presence manifested by illness and death. Poverty, in depriving people of access to health facilities, schools and media also limits their access to information and education on HIV/AIDS. Gerdes (1997) is of the opinion that poverty pushes families, often unaware of the risks, to send children into the workforce or to hand them over to recruiters promising work in a distant place where, unprotected, they might be forced into a childhood of harsh labor or sexual abuse. When HIV/AIDS appears in an already impoverished household there are limited means for response, the mortality rate is high, the impact is severe and the pressures and pain of poverty increase. As increasing numbers of infected young adults are unable to contribute to their communities through their work as parents, teachers, laborers, drivers, farmers, etc and so an entire economic and social structures of communities suffer and demands for services increase with fewer able people to provide them (Ahmed,1992).

Widows in-male oriented society are also at risk of more at financial exploitation and also have limited access to care should they become ill due to the lack of resources (Barolsky, 2003). Poor households carry the burdens of the impact of the virus. Congruent with a subordinate role, many women affected by HIV/AIDS belong to disadvantaged social groups, and experience the societal powerlessness associated with such membership (Campbell, 1990). Research has shown that women's fear of family conflict, violence and economic loss was a result of their effort to reinforce HIV/AIDS prevention strategies. Women are more likely than men to be poor and educationally disadvantaged, belong to minority groups, lack access health care and perceive less connection with community organizations (Bell, 1989). This socially sanctioned disempowerment places women at risk of contracting HIV/AIDS and contributes to the low profile given to the impact of

HIV/AIDS on women, specifically those women who are already infected (UNAIDS, 2004).

The death of the main breadwinner has immediate financial implications. First of all the funeral is an important ritual in African culture and is usually an occasion where all family members are expected to attend. It also has very specific financial implications and may place a huge burden on the remaining family members (HIV/AIDS Alliance, 2003). The impact on the surviving partner and children is usually extremely high. First the wife will have just survived nursing a chronologically ill partner and will probably be HIV positive herself. The family may lose its property as a result of the death of the father and children may be forced to leave school, as there would be no money for school fees (Boyd, Franklin, Steiner & Boland, 1995).

Tomaszski (2001) states that the economic and social consequences of the disease directly affect the rural family. The absence of well functioning medical care systems in many African countries implies that medical costs and caring for sick family members must be borne directly by the nuclear family or the extended family network.

2.4. PSYCHOLOGICAL MODELS FOR CHRONIC ILLNESS

People with chronic illnesses encounter a variety of psychological challenges that secondarily relate to the actual physical cause of the illness such as depression and anxiety (Sternberg, 1998 Franklin & Shontz 1975) cited in Sternberg (1998) proposed a stage model of how people react when they realize that they have a serious, chronic and probably a life threatening disease.

The first stage is of shock whereby individuals get shocked, stunned, bewildered and often feel detached from the situation. They respond by asking how, can this happen to me? The second stage is encounter; the person gives way to feelings of despair, loss, grief and hopelessness. During this stage, people are often unable to function effectively. They do not think well, they have difficulty in planning and they are ineffective in solving

problems. During retreat which is the third stage, individuals often try to deny the existence of the problem or at least the implications of what the problem means for them. Eventually, however people reach a fourth stage which is adjustment. During this stage individuals often try to make whatever adjustments are necessary to live with the reality of the disease.

Whereas, Franklin and Shontz's model focuses on the emotional and behavioural aspects of coping Taylor (1983 cited in Sternberg, 1998) has proposed an alternative model that highlight the ways people adapt cognitively to serious chronic illnesses. According to Taylor (1983), patients first try to find meaning in the experience of the illness. They may try to figure out what they were doing wrong that led to the illness and start doing whatever it is right or they may simply rethink their own attitudes and priorities in the light of their new perspective. Next patients try to gain a sense of control and power over the illness. They may seek as much information as possible about the illness and its treatment or they may undertake activities that they believe will help to restore function and well-being. Thirdly, patients may try to restore their self-esteem despite the experience of presenting with the illness. They may compare their own situations with those of others in ways that shed favourable light on their own situations. Although many people may pass the stages in the preceding models, individuals differ in terms of their effectiveness in coping.

Moos and Schaefer (1988 cited in Sternberg, 1998) described a crisis theory which attempts to characterize individual differences in people's abilities to cope with serious health problems. According to this model, an individual's coping mechanisms depends on three sets of factors.

- Background and personal factors such as emotional maturity and self-esteem, religious beliefs and age. Men are more likely to respond negatively to disease that compromise their ability to work. Older people will have to live fewer years with a chronic illness than younger ones and thus may be better able to cope with the prospects.

- Illness-related factors: such as how disabling, painful or life threatening the disease is. The greater the disability, pain and threat, the more difficulty people have in coping with the illness.
- Environmental Factors such as social supports, the ability of the person to remain financially solvent and the kinds of conditions in which the person lives. (Some factors may diminish the ability to cope whereas others may enhance).

According to Moos and Schaefer (1988 cited in Sternberg, 1998) the coping process has three main components: Cognitive appraisal, the individual assesses the meaning and significance of the health problem for his or her life. As a result of this cognitive appraisal, the individual may decide to perform tasks in a way that is adaptive, given the illness. In this way, the individual develops coping skills to deal with illness. The outcome of the crisis in general, depends on the whether the individual is able to live with the disabling illness. Ultimately the key to coping with serious chronic illness is adaptation. The individual will need to make changes and adjustments, to live happily and effectively. On the one hand, those people with serious chronic illness need to make more effort than the average person to adapt to the environment. Notwithstanding the fact is that everyone from time to time is confronted by a situation that requires varying degrees of adaptation to achieve relative psychological well-being.

2.5. THE IMPACT OF HIV/AIDS ON AFFECTED OTHERS

Even though the diagnosis of HIV/AIDS and the progression to chronic illness has a huge psychological and social impact on the person infected, the HIV/AIDS epidemic also has a detrimental impact on other family members.

2.5.1. Elderly people

There has been development in the provision of care and support services for the elderly, especially counselling and particular health needs and their legal position with regard to inheritance and property rights remain inadequate (Walsh, 1990). HIV/AIDS forces

children who take on the sole responsibility to care for siblings after parental death, grandparents similarly have to cope not only with the trauma of the loss of one or several young adult children, but also with series of escalated economic and care burdens precipitated by the death of adult children who may well have been breadwinners prior to their illness (Barolsky, 2003).

Once parents die the situation becomes worse for the children. In African families there is a strong sense of communal responsibility and it may be that other family members may take over the care of the children. The cultural expectation is that children will take care of their parents when they are old. Grandparents then have to take over of their grandchildren. In a case where parents are dead and the grandparents are no longer able to take financial responsibility for children, this may create financial as well as psychological burden for the elderly people (Mallard, 2007). The article on Afrol news (2004 cited in The Research Council of South Africa HSRC, 2006) reveals that the impact of the HIV/AIDS pandemic on the elderly has been underrated. The disease has 'placed' a heavy burden on older people on top of economic hardships such as high youth unemployment. The study found a high percent of orphans in South Africa being cared for by their grandparents. The elderly are the unseen heroes of the current pandemic, according to a study conducted on the elderly –age 60 and older in the South African province of Mpumalanga for the Department of health and Social Services (HSRC, 2006). The study investigated the socio-economic needs of the elderly in rapidly changing society, aiming to support from government departments and other service providers to the elderly people in Mpumalanga province.

2.5.2. Women

Cohen (2003) points to the fact that when women reveal a positive status this revelation has a far greater negative impact than in the case of a man. Some socio-cultural norms prevent both men and women from obtaining critical information about HIV/AIDS (Latif, 1989). For example, communities have a culture of silence around sexual matters and emphasize virginity from women and girls. The male domination of most heterosexual

encounters provides the cultural context within women have to negotiate strategies to protect their health (Bromme, 1995).

After a spouse's death, a mother is more likely than a father to continue caring for his/her children, and a woman is more willing to take care of orphans. Older women often shoulder the burden of care when the adult children fall ill. Later they may have to become surrogate parents of their orphaned grandchildren (HelpAge, 2003). AIDS-related stigma and discrimination often lead to the social isolation of older women caring for orphans and ill children, and deny them psychosocial and economic support.

When their partners or fathers die of AIDS, women may be left without land, housing or other assets. For example, in a Ugandan survey, one in four widows reported their properties were seized after their partners died (UNIFEM, 2004). A woman may also be prevented from using her property or inheritance for her family's benefit, which in turn impacts negatively on her ability to qualify for loans or agricultural grants. The denial of these basic human rights increases women's and girls' vulnerability to sexual exploitation, abuse and exposure to HIV.

According to the report on Global AIDS epidemic (UNAIDS, 2004), the impact of AIDS on women is severe, particularly in areas of the world where heterosexual sex is the dominant mode of HIV transmission. In sub-Saharan Africa, women are 30% more likely to be HIV-positive than men. The difference in infection levels between women and men is even more pronounced among young people. Population-based studies say that 15-24 year-old African women, on average, are 3.4 times more likely to be infected than their male counterparts.

Marriage and other long-term, monogamous relationships do not protect women from HIV. In Cambodia, it was reported that 13% of urban and 10% of rural men reported having sex with both a sex worker and their wife or steady girlfriend. Meanwhile, the country's 2000 Demographic and Health Survey found that only 1% of married women used condoms during their last sexual intercourse with their husbands (Cambodian

National Institute of Statistics/Orc International, 2000 cited in UNAIDS, 2004). The risk of this behaviour to wives and girlfriends is clear. In Thailand, a 1999 study found 75% of HIV-infected women were likely infected by their husbands. Nearly half of these women reported heterosexual sex with their husbands as their only HIV-risk factor (Bauer, 2000; Seidel, 1993). In some settings, it appears marriage actually increases women's HIV risk.

Women may hesitate to seek HIV/AIDS testing or fail to return for their results because they are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism. Studies from many countries, especially in sub-Saharan Africa, have found these are well-founded fears (Kelly, 2001). In Tanzania, a study of voluntary counseling and testing services (VCT) in the capital found, after disclosure, only 57% of women who tested HIV-positive reported receiving support and understanding from partners (Maman et al, 2002).

Many women feel they have no right to assert their own needs and desires in a situation where society defines the male partner's wants as paramount; they feel unable to assert their wish for safe sex, for fidelity or for no sex at all (Cossins, 2000). These beliefs do not only impact negatively on the women's' libido and sexual desire but they may also lead to her contracting HIV (Seidal, 1993). Most women have little power in sexual negotiations and are often limited in suggesting anything concerning sexual activities; and consequently to failure in HIV/AIDS prevention strategies which could meet their choices and actions. The common denominator is the subordinate role, with the degree of power being in part, culturally determined (Erben, 1990).

It is within the context of unequal power relations that women are required to take preventive and protective actions aimed at minimizing their risk of contracting HIV (Heckman, 1997). Because of potential transmission through heterosexual activity, where male to female transmission appears more likely than female to male, power issues related to sexuality are important (Karan, 1989). But in other countries research has

shown that some women are becoming increasingly assertive when it comes to their interactions with their sexual partners (Kline et al, 1992).

In many cultures, notions of masculinity are associated with pride; that emphasize multiple sex partners and a presumption of sexual knowledge (Reid, 1992). Some cultural practices which have sexual components or connotations, such as female genital cutting, widow inheritance and ritual cleansing, also increase vulnerability to HIV/AIDS (Reid, 1992). Other cultural and traditional practices and norms, such as circumcision and fidelity, decrease risk and should be part of prevention efforts (UNAIDS, 2000).

The denial and stigmatization of men who have sex with men in many instances leads males who engage in those activities to demonstrate their masculinity by having heterosexual sex as well, exposing their female sexual partners to HIV risk (Broome, 1989). Some male-dominated professions, which require long absence from home, such as truck driving, mining and migrant work tend to be associated with risky sexual behavior also put women back at home at being HIV/AIDS infected (Herek, & Glunt, 1988). At present there is the majority of the growing number of women with HIV/AIDS in Sub-Saharan Africa (Squire, 1993) whereby the migrant labor system, rapid urbanization and frequent “low intensity” wars have combined with growing landlessness and poverty to create an environment that is ripe for the spread of all sexually transmitted diseases and HIV in particular (Bauer, 2000).

According to Heath (2000), men must also be confronted with change. Responses to the AIDS crisis in the region have tended to focus on women because they are more vulnerable and are more likely to attend clinics and obtain information. However, this approach has not slowed the epidemic and there is a growing consensus that emphasis needs to be placed on male behaviour. The problem is that focus is on women who do not have the power to protect themselves because of the dominant role that cultural beliefs assume about male. It is therefore apparent that men are the key to HIV transmission and prevention.

2.5.3. Children

Freeman (2003) states that it is estimated that 2 million children in South Africa are infected with HIV. This poses many mental health challenges. Children may be infected by HIV, affected or even bothered. Cognitive deficits and failure to reach developmental milestones have been identified in children with HIV, and given that neurocognitive decline is often one of the first signs of HIV, this has important implications for identification and intervention. Significantly, it seems that neurocognitive decline is responsive to anti-retroviral intervention. The emotional impact of HIV on children needs to be researched. One area that may need particular attention are the psychological issues that arise for HIV/AIDS positive children when they reach puberty (UNICEF, 2003). The need to link with remedial education services was identified. Also the need to work with schools to foster acceptance of HIV positive learners and normalize their involvement in school activities was also highlighted. Social development issues, such as the need to move beyond AIDS shelters into more comprehensive programmes, were mentioned. In addition, the need to rationalize the childcare grant system was emphasized (Stine, 2001).

According to The United Nations Children's Fund (UNICEF, 2003), 14 million children under the age of 15 in the world have lost one or both parents to AIDS. By 2010, this number is expected to exceed 25 million. Without urgent, collective action, millions more children will face enormous risks in their struggle to survive. Across sub-Saharan Africa, where the HIV/AIDS epidemic is most severe, the extended family traditionally stepped in to take care of children who had lost their caregivers. But this traditional safety net is collapsing as a result of the impact of the HIV/AIDS crisis. More and more orphans are heading up their own households. However in South Africa, affected families are being helped with foster care grants and assistance to child-headed households (Ziel, 2001).

According to UNICEF (2003) many individuals and agencies are profoundly concerned about AIDS children who have lost one or both parents as a result of AIDS. It is deeply distressing to imagine that in the next decade African children will watch fearfully as their parents get ill, mourn them in their passing and struggle to pick up the pieces of

harsh future (Strode & Barret-Grant, 2001). In addition to the emotional consequences of living with a sick parent, children experience a gradual deterioration in the family household as their parents become sick and unable to work.

According to UNICEF (2003) when parents or caregivers fall sick and die, a child's life often falls apart. Many children have to take on the role of caring for a sick parent and for other siblings, which means they often drop out of school. This sets a destructive cycle in which an increasing number of children have no education, therefore no jobs, no career, no income and furthermore no families. The impact of HIV/AIDS upon child survival is likely to be much more severe than the impact on the overall population, causing more deaths than malaria or measles (Wijngaarden & Shaefers, 2002).

According to Heath (2000), projections of those children who will be orphaned by AIDS is extremely disheartening. In Kwa-Zulu Natal alone there are 250,000 AIDS orphans, which would rise to 900,000 by 2004. Traditionally orphaned children have been absorbed by their extended families. This system has continued to take in orphaned children even in the face of high HIV/AIDS rates. However, this system does have a high cost for both children and their caregivers. Studies have suggested that these orphans, even when cared for by their relatives, are at greater risk for poor health care, abuse and exploitation than non orphans. These AIDS orphans are more likely to have dropped out of school and to have worse nutritional status. They also face a lack of or minimal availability of shelter, lack of stable source of income, a poor or lack of psycho-social support, detachment and desocialization (particularly street children), and abuse (UNAIDS, 2002).

The pandemic condemns these orphans to poverty and social stresses when they grow to adulthood and limits their economic prospects as well as those of their families, communities, and country. The epidemic has also placed a tremendous strain on providing substitute care for orphans. These are mainly female relatives, most of whom are poor and elderly. AIDS in Africa is often referred to as the 'grandmother's disease' as in most cases elderly women are often required to attend to ailing children and support

their grandchildren in the form of school fees, uniforms, food, shelter and nurture. These relatives and caregivers often suffer financial stress, emotional trauma and overcrowding (UNICEF, 2003).

2.6. RURAL ISSUES

2.6.1. Operational Definition: Rural

According to Jackson (2002), rural areas are sparsely settled places away from the influence of large cities. Such areas are distinct from more intensively settled urban and suburban areas, and also from unsettled lands. Rural area can also be characterized by the number of people per square mile (population density). An area with a low population density can be determined as more rural than a place that has a high population density. In modern usage, rural areas can have an agricultural character, though many rural areas are characterized by an economy based on logging, mining, petroleum and natural gas exploration, or tourism.

Lifestyles in rural areas are different from those in urban areas, mainly because limited services, especially public services are available. Public services such as police services, schools, fire stations, and libraries are generally available, but may be limited in scope, or unavailable in remote communities. Utilities like water, sewerage, street lighting, and public waste management are generally present in larger settlements.

2.6.2. Characteristics of rural areas

According to Herselman (2003), many of South Africa's rural areas exist below subsistence levels and remain impoverished because:

- They have no access to basic infrastructure essential for economic growth and development.
- They lack basic infrastructure such as electrical reticulation and communications essential pillars for economic growth has not even been planned for many deep rural communities in South Africa.

- The location place limitations on access to information and the use of internet, which are considered vital to the promotion of learning, training and business development in developing communities.
- The development of the local economy in South Africa, and Africa in general, is severely compromised by the lack of infrastructure, services and know-how.
- Without telecommunications, no current market information is available, and know-how cannot be transferred.
- Large number of people from the rural areas migrates to the urban area to seek job opportunities. Many are forced to return to the rural areas due to the pressure of limited job opportunities in the country as a whole.

2.6.3. HIV/AIDS in Rural Areas

The Health Resources and Services Administration (HRSA, 2003), states that although most HIV/AIDS cases continue to be in cities, more cases are been reported in rural areas. This requires service delivery systems to meet such unique needs as transportation to bring clients to services across large geographic areas and training to increase a number of HIV/AIDS service providers. Multiple obstacles may hinder the development of HIV/AIDS care programmes, however. Inattention to HIV/AIDS may be caused by underreporting of cases (e.g. PLWA from urban areas who return to their rural homes). Some PLWHA may fear breach of confidentiality and seek services outside their area.

According to UNAIDS (2006) during the early stages of the epidemic, it was predominantly an urban problem, affecting more men than women and those with relatively lower incomes. Now the epidemic has rapidly moved into the rural areas, hitting those who are less equipped to deal with its consequences. Today 95% of people living with and dying of HIV and AIDS are in developing countries. The overwhelming majority are the rural poor.

The Social Science Research Council (SSRC, undated) points out that HIV/AIDS is clearly a rural issue now, of the 36 million people living with the pandemic, an

overwhelming percent live in developing countries. And within those countries AIDS is becoming a greater threat in rural areas than in cities. In absolute numbers, more people living with HIV reside in rural areas. The epidemic is spreading with alarming speed into the remote villages, cutting food production and threatening the very life of rural areas and communities. AIDS undermines agricultural systems and affects the nutritional situation and food security of rural families. As adults fall sick and die, families face declining productivity as well as loss of assets. In addition, rural communities bear a higher burden of the cost of HIV/AIDS as many urban dwellers and migrant labourers return to their village of origin when they fall ill. At the same time household expenditures rise to meet medical bills and funeral expenses and while the number of productive family members decline, the number of dependents is growing (Bepura, 2000).

Bepura (2002) argues that the dynamic interaction between AIDS and the agricultural systems that are central to rural communities are among the most worrisome, especially with regard to poverty conditions in certain regions for which AIDS bears much of the blame. The loss of the productive members of households forces new and possibly irreversible choices on food production and the sale of assets such as livestock. It is being understood that the impact on individual households can be severe, but the dynamics will eventually challenge whole rural communities. In much of Africa, production activities are communal. Even where they are not, the rising number of orphans, widows with insecure rights and rising burdens of care will threaten the social and economic fabric of rural communities.

In addition to challenging the sustainability of rural economies, HIV/AIDS is also transforming the social structures of communities. With the breakdown of households and rising number of orphans and those in need of care, villages need to adapt not only to economic burden, but to the social implications of the epidemic as well (UNAIDS, 2006).

Food and Agriculture Organization of the United Nations (FOCUS) (undated) mention that the biological and social factors make women and girls more vulnerable to HIV and

AIDS than men and boys. Studies have shown that HIV infection rates in young women can be 3-5 times higher than among young men. Also some of the traditional mechanisms to ensure women's access to land in case of widowhood contribute to the spread of HIV/AIDS such as the custom that obliges a man to marry his brother's widow. Women and girls also face the greatest burden of work given their traditional responsibilities for growing much of the food and caring for the sick and dying. In many hard hit communities, girls are being withdrawn from school to help lighten the family loads.

The impact of AIDS on farming communities differs from village to village and country to country. It is without doubt that the epidemic is undermining the progress made in the last 40 years of agricultural and rural development. This poses challenges to governments, non-governmental organizations and the international community. The disease is no longer just a health problem; it has become a major development issue (Bepura, 2002). The small number of reported cases of HIV/AIDS in rural areas can perpetuate the denial of many community leaders and health care professionals that HIV/AIDS is a significant concern. Since funding is often based on the number of reported cases in an area, inaccurate reporting can hinder efforts in rural areas to secure funding for HIV/AIDS care. Denial that HIV/AIDS is a problem and lack of skilled knowledgeable HIV/AIDS information providers are two of the major barriers to HIV/AIDS care in rural area (Doka, 1997).

According to Rural Center for HIV/STD Prevention (RCAP) (1997) people living in rural areas reported significantly lower satisfaction with life than their urban counterparts, according to a recent study that investigated the psychosocial differences between rural and urban persons with HIV/AIDS. The study conducted by the Center for AIDS Intervention Research of the Medical College of Wisconsin, surveyed 276, persons with HIV/AIDS in the United States of America. The questionnaire measured respondents' quality of life, perceptions of loneliness, social support, experience with AIDS related discrimination, access to service and illness-related coping strategy. The rural persons living HIV/AIDS in contrast to similar urban residents had a lower perception of social support from family members and friends. They also had limited access to medical and

mental health care, elevated levels of loneliness, more community stigma and more maladaptive coping strategies. The study concluded that programmes designed to improve the circumstances of persons living with HIV disease in rural areas, particularly those that facilitate access to adequate health care, increase perceptions of social support and improve illness-related coping are urgently needed.

Health care professionals who are available to provide care to PLWA remain in short supply, in rural areas. Common reasons are lack of knowledge about the disease and limited access to specialists for consultation and burnout. The limited number of rural primary care doctors with experience in treating HIV disease represents a major void in the continuum of care for PLWHA in these areas (HRSA, 2003).

2.7. FAMILY ISSUES

2.7.1. Operational Definition: Family

Goldenberg (2000) claims that families can be constructed in many ways. The history of South Africa has led to the development of many different family structures ranging from the extended family to the nuclear family with many variations in between. The Oxford Dictionary of Sociology gives a definition of what a family is as follows. The family is an intimate domestic group made up of people related to one another by bonds of blood, sexual mating, or legal ties (Barolsky, 2003). According to Mckenry and Price (1994) the families are in groups that construct individual meanings and shared meanings. There are several characteristics that reflect the unique nature of families as social groups.

Goldernberg (2000) indicates that a family is more than a collection of individuals sharing a specific physical and psychological space. While families occur in a diversity of forms today, each may have a set of rules, has assigned and ascribed rules for its members and has an organized power structure. It has developed intricate overt and covert forms of communication, and has elaborate ways of negotiating and problem solving that permit various tasks to be performed with varying degrees of effectiveness.

The relationships between members of this microculture are deep and multilayered, and are based largely on a shared history; and a sense of purpose. Within the family system, individuals are tied to one another by powerful, durable, reciprocal emotional attachments and loyalties that may fluctuate in intensity over time but nevertheless persist over the lifetime of the family.

Bor and Elford (1998) observe families create and indoctrinate new members, and although they ultimately give these members autonomy and no longer expect them to live under the same roof, family membership remains intact for life. They contend that the power of the family is such that despite the possible separation of members by vast distances, sometimes even by death, the family's influence remains present. Even when a member experiences a temporary or permanent sense of alienation from one's family, he or she can never truly relinquish family membership (Wijgaarden & Shaefer, 2002).

2.7.2. Characteristics of a Family

Prochaska (1984) identifies the following characteristics of a family: A family has a sense of privacy, a collective consciousness that is not readily available to those who are not part of the family. This also includes relationships rooted in blood ties, adoption contract, marriage, shared traditions, intense involvement ranging from the most violent to the most intimate and understanding individual interests, experiences and qualities (Prochaska, 1984). Levine and Perkins (1997) claim that African families differ from western families.

Goldenberg (2000) further points out that in the process of growing up, family members develop individual identities but nevertheless remain attached to the family group, which in turn maintains an identity or are interdependent on one another-not merely for money, food, and shelter, but also for love, affection, companionship, socialization, and other no tangible needs. Families maintain history by telling and retelling their "story" over generations, thus ensuring continuity and shaping the expectations of members regarding the future. To function successfully, members need adapt to changing needs and demands

of fellow family members as well as changing larger kinship network, the community, and society in general (Barolsky, 2003; Gerdes, 1997; Hervis, Szapoenick, Mitrani, Rio & Kuirtness, 1991).

Apart from its survival as a system, a well-functioning family encourages the realization of the individual potential of its members-allowing them freedom for exploration and self-discovery along with protection and the instillation of a sense of security distinguishes between what he calls “enable” and “disable” family system (Cossins, 2000). The former succeed at balancing system needs as a family unit while simultaneously operating on behalf of the interest of all its members as individuals. Enabling family regimes inevitably invent procedures that attempt to satisfy the sometimes conflicting interest of its members. Goldenberg (2000) maintains that to do less, or to prevail but only at the expense of certain members, reflects family disablement, often manifested in unstable or chaotic family patterns (Prochaska, 1984). Ku (1993) claims that in China rural families are currently categorized into four types according to their structure:

- Nuclear families, consisting of married couple with unmarried children or of a married couple without children
- Lineal families, consisting of two or more generations with each generation composed of one married couple
- Joint families, consisting of two or more married couples.
- Other types including single-person families consisting of siblings, relatives and friends.

2.7.3. HIV/AIDS and Families

At the heart of the social context is the family. The family, both as an ideal and structural phenomenon, constitutes probably one of the most fundamental building blocks of the society, the glue that holds communities in bonds of complex interdependence (Broderick, 1993). Broderick (1993) further states that the family as a pre-existing network of care could constitute one of South Africa’s most important social network in

the country's attempt to address the consequence of the epidemic. However, the main emphasis when looking at the impact of HIV positive diagnosis has been on the individual. The belief is that the impact on the family can be just as devastating and would consequently affect the type of support that the HIV-positive person may receive (Barolsky, 2000; Murray, 1956).

According to Goldernberg (2000), families vary with respect to the permeability of their boundaries. They are typically thought of as being the most closed and private of all social groups. Families have conflicts in the process of preserving and protecting their traditions, secrets and habits. Keeping sexual and dysfunctional behaviours from outsiders is a key mechanism by which families construct and maintain their unique self-definitions. Macklin (1989) further states that the family, both as a social institution and a unit of intimate expression, has a unique position within human culture. Families provide socialization for their members across the lifespan, teaching them the values and the roles important for human development.

2.7.4. Family Structures

Families are organizationally complex emotional systems that may comprise three and increasingly today as a result of longer life expectations, four generations. A family attempts with varying degrees of success, to arrange itself into as functional group as possible so that it can meet its collective or jointly defined needs and goals without consistently or systematically preventing particular members from meeting their individual needs and goals. In order to facilitate the cohesive process, a family typically develops rules that outline and allocate the roles and functions of its members. Those who live together for a period of time develop proffered for negotiating and arranging their lives to maximize harmony and predictability (Broderick, 1993). He further postulates that affection, loyalty and durability of membership characterize all families and then distinguish them from other social systems. Even when these qualities are challenged, as in a family crisis situation or where there is sever conflict between members, families are typically resistant to change and are likely to engage in corrective

manners to reestablish familiar interactive patterns. Regardless of format or ultimate success, all families must work at promoting positive relationships among members, attend to personal needs and prepare to cope with developmental changes as well as unexpected crisis. In general, all must organize themselves in order to get on with the day-to day problems of living. More specifically, all must develop their own special styles of coping with stresses imposed from outside or from within the family itself (Goldenberg, 2000).

Bor and Elford (1998) claim that family problems change and stress responses are not necessarily bad for the family. The imbalance that develops requires new methods for handling problems. Out of this situation may trigger new creative solution for organizing activities that are effective to those that were present before the problem emerged. These experiences may enable the family to handle future crises in a effective manner thereby resulting in greater individual and group satisfaction with the family. Not all families can handle problems in an effective manner.

The HIV/AIDS epidemic is felt most at the level of families. It is within the family that people living with HIV and AIDS will need to be able to disclose their status and to be cared for and supported. Decisions will need to be made about allocation of resources, which will determine how each family member will be affected. Parents who are living with HIV and AIDS need to come to terms with the fact that they may die and leave young children who need to be cared for by the extended family and community networks (Bouer, 2000).

It may happen that children are separated from each other as one family may not be able to handle the financial responsibility thereby, adding more psychological distress (Jackson, 2002). Losing one member of the family can cause psychological stress to the surviving family members. Various factors can cause stress, including the knowledge that the loved one is going to die. This could be worse if the person is still young compared to when the person is older (Roberta, 1989). Secondly the stigma by communities around HIV and AIDS issues contribute to psychological distress on those who are close to the

infected person. The family members may also suffer psychological distress if they themselves hold stigmatizing beliefs towards PLWHA and this may contribute to change in the structure of the family as well as relationships amongst family members (Bor & Elford, 1998).

Bor and Elford (1998) further point out that the family is not a neutral space, but a context in which power is contested and exercised in daily negotiations between members. Sometimes the exercise of power within the family is brutal and violent, sometimes it is exercised with love and care to socialize and nurture. Understanding the impact of HIV/AIDS on this does not make easy generalization possible, but at the heart of HIV epidemic it is difficult. This is where the consequences of the epidemic are played out, where those who are sick hope, but do not always find nurturance through illness and death, where family members who are not infected are faced with reality which challenges familial bonds.

2.7.5. Family Resilience

A family as a whole, or one or more of its members, may manifest dysfunctional behaviour during periods of crises or persistent stress, but that is not to say that the system or its component members are necessarily without strengths and resources or lack those interactive processes that strengthen family hardiness (Goldenberg, 2000). While some families are shattered by crisis, others emerge strengthened and resourceful. Rather than classify a symptomatic family member as a vulnerable victim, thus pathologizing the family, an emerging viewpoint is that while problems may certainly exist within the family, family competencies can be used to promote self corrective changes. Resilience should not be thought of as a static set of strengths or qualities, but more a developmental process unique to each family that enables families to create adaptive responses to stress and in some cases to thrive and grow in the response to the stressors (Hawley & deHaan, 1996). Adopting a resiliency based approach in working with families call for denitrifying those key interact ional process that enables families to withstand and rebound from disruptive challenges (Walsh & Bibace, 1990).

All families face challenges during their life cycle, some are expectable strains, while others are sudden and untimely. How the family organizes itself, how it retains its cohesion, how openly it communicates and problem solves together to cope with the threat are crucial to its functionality. The support of a network of friends, extended family and the availability of community resources often contribute to family recovery. Even chaotic, disorganized, abusive and multi-problem families have resources. Karpel (1997) cited in Goldernberg, (2000) refers to the rootedness, intimacy, support and meaning a family can provide. In poor families, especially, the members need to feel self-worth, dignity and purpose; resilience is facilitated for them if they experience a sense of control over their lives rather than viewing themselves as helpless victims of an uncaring society.

2.8. COMMUNITY

According to Bepura (2000), the poorest communities in our areas are often the ones that are expected to carry the heaviest burden as a result of HIV/AIDS. It is in poor communities where more people die and where relatives, neighbours and grandmothers are expected to provide the extra care, money and food needed by children orphaned by HIV/AIDS. The burden of looking after the ill who cannot afford medical care also falls on the poor. While so many people are dying from AIDS the of poor families are increasing because families that are intact often take in children who are related to them who have lost their parents. It is in the poorest communities where orphans also pose a potential threat in terms of social stability. Children leaving in child-headed households or on the streets lack adult parental guidance, support and discipline. Out of depression they may turn to crime. There are already areas in South Africa country where orphans and old people outnumber the economically active adults. This also has serious implications for the elderly who rely on their own children for support during old age (Barolsky, 2003).

Lack of education about HIV/AIDS in the community level results in a lack of community support for HIV/AIDS prevention and treatment programmes, which can make local officials reluctant to support programs or implement positive public policy.

Educational efforts should focus on allaying fears and answering questions about the HIV condition and should reframe issues in a way that will result in positive local responses. Educational programmes should provide information on the following:

- Psychosocial aspects of HIV/AIDS (e.g., denial, anxiety, discrimination, isolation) and
- Impact of HIV diseases on both individuals and their families. In addition, educational programs should challenge people to confront their fears and negative attitudes about PLWA and their families.

2.9. STIGMA AND DISCRIMINATION

Before stigma and discrimination can be discussed, a definition of these two terms will be provided. Stigma, according to Edgar and Sedgwick (1999, p.81), “is a culturally recognized attribute that is used to differentiate and discredit a person. The stigma may be physical (a bodily deformity), behavioural (for example, a sexual preference), or social (in the sense membership of a group). The identification of the stigma is used to reduce the person from a complex whole, to a single, tainted and discounted trait, upon which all social interaction with the person will be based”. In other words, stigma is associated with an attitude that can affect people at several levels. Inevitably, stigma leads to discrimination which is an enactment of the attitude. Thus stigma makes itself felt through discriminatory behaviour, where the individual is not fully accepted socially and is in fact discredited, and in many instances seen as having a failing, shortcoming or a handicap (Goffman, 1963).

2.9.1. Origins of Stigma

According to Strode and Grant (2001), the origins of stigma may be conceptualized as follows: Stigma arises from moral attitudes and systems of sex-belief and morality are closely linked in our society. HIV/AIDS are seen as punishment and just retribution for immoral behaviour and people want to dissociate themselves from this. Ignorance and a lack of knowledge usually lead to irrational fear and behaviour.

Goffman (1963) further states that discrimination occurs when there is a right or privilege a person is normally entitled to is denied because the person is HIV positive. Examples of discrimination are losing one's job, being shunned by friends and family and even being denied service. The effects of stigma are felt at three levels. At the individual level, this causes anxiety and distress both of which contribute to ill health and thus do not help the situation of the person living with HIV/AIDS. The second level is at the family level which affects how the family deals with the person living with this condition. At the third level, the community becomes involved. The effects of stigma at this level can cause whole families and groups to feel ashamed and they will try to conceal their association with the epidemic.

2.9.2. Children and Stigma

According to and UNICEF (2003) children who lose their parents to HIV/AIDS, may suffer prejudice and social exclusion in addition to loss and grief like any other orphan. The shame, fear and rejection suffered by PLWHA can create additional stress and isolate children before and after the death of their parents. In fact, Bradshaw, Johnson, Scheider, Bourne and Dorrington (2002) found that orphanhood started before the death of a parent. If there is only one parent and that parent becomes ill with HIV/AIDS, the household is without income as the parents are no longer able to support the child. This trauma of watching the slow death of the parent is one of the first stressors that orphans have to face. In addition, Strode and Grant (2001) believe that children with HIV are more vulnerable than adults because they might have stigma relating to their own status as well as the stigma that might be associated with their parents or caregiver. According to the research report by Grant and Grant (2001), children suffer two main forms of stigma and discrimination. Firstly, they suffer general stigmatization and isolation by families, communities and institutions within communities (Jackson, 2002).

Secondly Jackson, (2002) furthermore states that the HIV/AIDS infected person may not be aware that he is sick for a long period of time and subsequently spreads the infection to other people. Should the diagnosis be made the changes are that the information will

be kept a secret because of fear of rejection from the larger community. However, the secrecy may become more difficult to handle when the person gets ill and begins to look for help. The person may seek for help by visiting a 'sangoma' or a traditional healer who may give the person herbal portions. This is because some of black individuals still do not view HIV/AIDS as an illness, but rather as some sort of bewitchment (Barolsky, 2003).

According to Robbins et al. (2003), researchers are increasingly recognizing the protective role of social support in PLWHA. For example, PLWHA report fewer feelings of helplessness and depression if friends or relatives are available to discuss emotional and illness- related issues with them. They further mention that family functioning is associated with a variety of positive interactions.

2.10. STRUCTURAL AND SOCIAL SYSTEMS THEORY

Mckenry and Price (1994) view families as living organisms with both symbolic and real structures. They have boundaries to maintain and they have a variety of instrumental and expressive functions to perform to ensure growth and survival. The structural family systems theory indicates that HIV/AIDS like any other behaviour should be understood from the context within which it occurs, which is the family. A family is a system and like any other system, it has elements whose sum of parts forms a whole. Thus wholeness is greater than the sum of its individual parts meaning that the family's interaction is more important than the separate needs of each member (Broderick, 1993).

The family as a system constitutes boundaries as well as each subsystem. And the family has a way of regulating these boundaries in times of stress and is also capable of changing its structure, e.g, when a member dies or when parents die children are taken to stay with extended family members. As any social system, a family strives to maintain a steady state as they are the product of sub-systems (Minichun, 1967).

2.10.1. Disengaged Families

In a disengaged family, excessively rigid boundaries make interactions with other systems or subsystems almost non-existent. Every family member lives his own separate life. Mothers in these families are usually passive, inactive, unable to care for the children, have self critical and self pity notions and are often depressive and psychosomatic (Prochaska, 1984). When looking at the psychosocial and emotional reactions that result from the HIV/AIDS experience, depression is one of the emotional responses that infected people normally experience.

A systems approach allows the researcher to focus beyond the family and the individual to the wider social system. Families do not live in isolation; they are part of the larger social context. This external environment in which a family is embedded is referred to as the ecosystem. Thus living in a particular historical period, its cultural identification, the economic conditions of society, its genetic stamina and resistance and its stage influence the family's response to a stressor in the family life cycle (McKenry & Price, 1994).

This theory also uses family stress model that in case of a stressful situation the family's stress level can be managed and the family can return to a new equilibrium. But the family's resources mediate the impact of the stressors event on the family. In case of rural families, the resources might be lacking as some people still do not know about the antiretroviral medication and the social grants (Minichun, 1967). This will definitely have an impact on the family's ability to prevent a stressful event or change from creating disruptiveness in the system because members do not have appropriate resources to protect the family from the impact of stressors and facilitate family adaptation during family stress or crisis (Broderick, 1993).

The impact of the stressor on the family's stress level is also mediated by the definition or meaning the family gives to the event. It is found that families who are able to redefine a stressor more positively appear to be better able to cope and adapt. By redefining the stressor, families are able to clarify the issues, hardships, tasks to render them more

manageable and responsive to problem solving efforts. They are also able to decrease the intensity of the emotional burdens associated with the HIV/AIDS stressor and as well as encouraging the family unit to carry on with its fundamental tasks of promoting an individual member's social and emotional development (Mckenery & Price, 1994).

Mckenery and Price (1994) are of the opinion that families have different ways of coping with stressful events and a family's coping has been conceptualized in terms of three responses, namely; direct direction, intrapsychic, and controlling the emotions generated by the stressors. The family's coping behaviour involves the management of various dimensions of the family life simultaneously thereby is; maintaining satisfactory internal conditions for communication and family organization, promoting member independence and self esteem, maintenance of family bonds and the maintenance and development of social support networks.

With adequate support, PLWHA are able to respond adequately to the stress of being infected and are less likely to present with serious mental health problems. HIV infection can often result in stigma and fear for those living with the infection, as well as those caring for them, and may affect the entire family. Infection often results in loss of economic status, employment, income, housing, health care and mobility. Psychosocial support can assist people in improving the quality of their lives, and may prevent further transmission of HIV infection.

According to Levins and Perkins (1997), family members must deal with a number of problems that arise when a member is diagnosed as having HIV/AIDS. It is important to realize that each family member confronts social isolation from the established family unit; the neighborhood, the larger community and the macro political system and they also have to deal with new changes after the death of the loved one.

2.10.2. Critical evaluation of the structural social systems' theory.

The strengths of this theoretical framework are its fulfillment of a requirement of a theory. The social system's theory has conceptual definitions, to state relationships, which may describe and explain or even control a stressor. It may not fit all the requirements for a scientific theory, whose validity and reliability has been tested, it can at least be regarded as a substantive theory (Broderick 1993). Because some of its concepts have been validated through replication studies. However the study employs most of the western concepts in terms of families and HIV/AIDS, it fails to recognize that HIV/AIDS in African families is not just a simple stressor that one can just cope with easily, as people are experiencing multiple losses, and therefore it needs more attention.

2.11. ATTACHMENT THEORY

Attachment relationships appear to be of special importance for the maintenance of feelings and of security. The loss of any attachment relationship, especially of a child's mother, tends to lead to separation protest, which brings about a sense of helplessness and fear. The presence of attachment seems to buffer many of the devastating effects that could take place within a child. It would seem that attachment is critical to a child's sense of security as well as the maintenance of emotional stability (Parkes, Stevenson-Hinde & Marris, 1991).

An attachment is an affectional bond, while an attachment figure is never interchangeable or replaced by another person. Attachment is the first crucial relationship where human beings organize meaning (Dryden, 1996). Bowlby (1985) cited in Dryden (1996) has stated that the accessibility of parental figures is capable of sustaining children's feelings of security. In attachment, there is a need to maintain proximity, distress upon separation, pleasure or joy at reunion and grief at loss. When children feel threatened or anxious, they usually display attachment feelings and behaviours, and the attachment figure can never be replaced no matter how caring the other figures may be. When parents have died attachment feelings will always be displayed.

When the mother provides the child with security and comfort, the child will be able to move from the secure base provided by the mother, with confidence to engage in other activities. Since a human's well-being depends on securing the protection of attachment figures, its unresolved insecurities can linger onto other areas of life and well into adulthood (Parkes, et al, 1991).

Attachment involves an interaction between the child and his parents, through which each learns a set of strategies by which to manage the relationship. The child has to figure out what he needs to get from his attachment figures and accomplishes this by making a fuss or working the system (complying with adult rules) (Parkes et al, 1991). Alexandra (1992) suggested that there are also other relationships besides a child's relationship to his parents that contribute to a sense of security and worth, and provide comfort, especially in stressful situations. These can be friendships or other relationships within the child's community (Parkes et al, 1991). Interestingly though, children between the ages of 5 and 8 years do not seem to have the ability to reflect about relationships and friendships to put them into words even though these feelings are present from a young age (Parkes et al, 1991).

Parkes et al (1991) go on to argue that when a child is lonely and isolated from the rest of his family and friends, the presence of his mother may not even make up for feeling without sense of belonging in a community (Parkes et al, 1991). Loneliness can be produced by the absence of an attachment figure (such as the child's mother) as well as by an absence of relationships of a community (such as a child's school friends).

Bowlby (1987) cited in German (2004), states that the mourning process of children resembles the separation process and is divided into three phases: protest, despair and detachment. In the protest stage, a child has a strong need for the mother or other caregivers who died and cries for their return; in the despair stage, a child starts losing hope about the mother's return, he cries and withdrawal and apathy set in. In the detachment phase, a child begins to relinquish some emotional attachment to the dead parent and exhibit a reawakened interest in the surrounding. In dealing with a bereaved

child, the health care and social services professionals should recognize the child's need to find a person to substitute for the lost parent. Children may transfer their need from a parent to several adults rather than one. If there is no consistently available person, severe psychological damage may result to such an extent that the child may no longer seek for or expects intimacy in any relationship. The importance of managing grief reactions in children is highlighted by the increased evidence that depressive disorders and suicides attempts occur more frequently in adults who experienced the death of a parent in early childhood (UNICEF, 2003).

Uncertainty arises when one can no longer make sense of what is happening around them. One becomes uncertain when events are unpredictable, when they disrupt the purposes that make action meaningful (such as loss of an attachment figure), and when there is a breakdown of organization through internal contradictions. The measure of a child's failure to handle these uncertainties may cause anxiety, defensiveness, depression and grief (Parkes et al, 1991).

The great strength of attachment theory is that it focuses on a system of behaviour that takes into account biological, cultural and psychological perspectives. This implies a search for basic processes of functioning universal in human nature, especially for a culturally diverse country such as South Africa.

2.12. Erikson's Psychosocial Stages of Development

Although Erikson (1963) referred to his developmental stages as crisis', these are not crisis' but are rather critical times in the developmental sense of challenges, turning points of maturation through which we can trace the pattern of an individual's personality. Each step in the cycle of life presents the individual with a new life task, a set of choices and tests which are prescribed by the structure of the culture and society in which he or she lives (Erikson, 1963). The successful resolution of such challenges leads to the gaining of what Erikson calls virtues. In what follows Erikson's eight stages of

psychosocial development will be discussed and they will be integrated with how death has an impact on individuals.

Stage1: Trust versus Mistrust (birth to 1 year).

Infants learn either to trust or to mistrust that their needs will be met. They come to view the world as either basically friendly or basically hostile. Successful passage through this stage leads to the development of a *hopeful* attitude toward life and what can be expected from it.

Stage 2: Autonomy versus Shame and Doubt (ages 1-3).

Children learn to exist within the expanded horizons of the environment. Those who do not master this stage doubt themselves and feel shame about themselves and their abilities in general. Those who do master the challenge become self-sufficient in walking, talking, eating, going to the toilet, and so on. Successful passage through this stage leads on the development of the *will*-a sense of control and mastery over their emotions, thoughts, and behaviours.

Stage 3: Initiative versus Guilt (ages 3-6)

Children learn how to take initiative and to assert themselves in socially acceptable ways. However, children whose independence leads to excessive or unresolved conflict with authority figures may feel guilty and may have difficulty in taking initiative. Successful passage through this third stage engenders a sense of purpose in life.

Stage 4: Industry versus Inferiority (ages 6-12)

Children have a sense of capability and of industriousness in their work. Those who do not develop this sense develop feelings of incompetence and low self-worth; they may be feeling unable to do many things well. A child who successfully passes through this stage develops a sense of competence.

Stage 5: Identify versus Role confusion (adolescence)

Adolescents try to figure out who they are, what they value, and who they will grow up to become. They try to integrate intellectual, social, sexual, ethical, and other aspects of themselves into a unified self-identity. Those who succeed develop a sense of *fidelity* to themselves. Those who do not remain confused about who they are and what to do with their lives.

Stage 6: Intimacy versus Isolation (early adulthood)

The emerging adult tries to commit him or herself to a loving intimate relationship. The adult who succeeds learns how to *love* in a giving and non-selfish way. The adult who fails develops a sense of isolation and may fail to connect with the significant others in his or her life.

Stage 7: Generativity versus stagnation (middle adulthood)

Adults try to be productive in their work and to contribute to the next generation, whether through ideas, products, raising children, or a combination. This productivity is termed *generativity*: Adults who do not succeed in passing through this stage become stagnant and possibly self-centered as well, leaving no lasting mark for having been alive (Erikson, 1963).

Stage 8: Integrity versus Despair (old age)

People try to make sense of the lives they have led and, in particular, of the choices they have made. They may not feel as though every decision was right, in which case they must come to terms with their mistakes. Adults who succeed in this stage gain the wisdom of older age. Adults who fail may feel a sense of despair over mistakes or lost opportunities (Erickson, 1963).

The stages of children's emotional development play a significant role in their understanding and perception of death. Between the ages of 5 and 10 years children have a developing sense of inevitable human mortality; they fear that their parent will die and that they will be abandoned. About the age of 9 or 10, children understand death. Usually

by puberty children conceptualize death as universal, irreversible and inevitable as do adults. However, the separation of a child from his or her mother is a traumatic event and can hinder some of the psychosexual developmental stages. Sometime the child can be fixated to move to the next stage as the loss is just too painful to conceptualize so he stays fixated at a stage that he feels safer (Sternberg, 1998; Walsh, 1990, 2003).

Unlike children and teenagers, older adults often readily accept that their time has come. Elderly patients may talk or joke openly about dying and sometimes welcome it. In their 70s or beyond, they no longer harbor illusions of indestructibility; most have already had several close calls, their parents have died, and they have gone to funerals for friends and relatives. Although they may not be happy to die, they can be reconciled to it (Walsh, 1998).

According to Erikson (1963 cited in Sternberg 1998), the eighth and final stage in the life cycle brings either a sense of integrity or despair. As elderly adults enter the last phase of their lives, they reflect on their time and how it has been lived. When one has taken care of things and relatively successful and adapted to the triumphs and disappointments of life, one can look back with satisfaction and only a few regrets; one experiences a sense of integrity about oneself, feeling that one has lived totally and well and that one's life has been meaningful (Erikson 1963). Erikson (1963) furthermore states that integrity of the self allows an individual to accept inevitable disease and death without fear of succumbing helplessly. However, a person who looks back on life as a series of missed opportunities or as filled with personal misfortunes has a sense of bitter despair, a preoccupation with what might have been if only this or that had happened; then death is viewed with fear, because it symbolizes emptiness and failure.

2.13. CONCLUSION

This section discussed different ways in which HIV/AIDS affects the psychological well being of individuals and emotional reactions that infected people endure after the diagnosis. The researcher also looked at how it impacts on significant others, which is the

family as a whole, children and youth as well as adults. It also looked at stigma as a separate issue that perpetuates the difficulty in coping with being HIV infected as well being affected with the pandemic. Different theoretical frameworks were discussed to how HIV/AIDS infection impacts on families and individuals within the family.

CHAPTER 3

METHODOLOGY

3.1. INTRODUCTION

This chapter gives an outline of research methods that were followed in the study. It provides information on the participants, that is, the criteria for inclusion in the study, who were the participants, where and how they were sampled. The chapter includes the setting in which the study was conducted. The researcher describes the research design that was chosen for the purpose of the study and the reasons for this choice. The instrument that was used for collection is also described and the procedures that were followed to carry out this study are included. The researcher also discusses the methods used to analyze the data. Lastly, the ethical issues that were followed in the process are also discussed.

3. 2. THE SETTING

The sample of the present study was drawn from Saint Rita's hospital in the Sekhukhuneland area called Glen-Cowie. Sekhukhuneland is a small area in north-eastern South Africa in the province of Limpopo and Mpumalanga. The region was named after Sekhukhune the First, who was the chief of the Pedi tribe when land rights were granted to them in 1885. Thereafter it became part of the former self-governing homeland of Lebowa (Botha 1945 Cited in Victor, Siebert, Hoare & Van Wyk, undated).

Glen-Cowie farm was a farm that was bought from Kuhlman family by the Perfect Apostolic. Kuhlman was a German who was married to a Scottish lady whose surname was Cowie. The farm was named after her. In 1935 three Roman Catholic brothers established a mission. In autumn of the very same year three Loreto nuns one of them being Sister Rita arrived at Glen-Cowie. The sisters started to visit the surrounding villages by foot. The inhabitants were at first timid and afraid of strangers. Each day the

sisters plodded through the fields visiting the villages and administered to the needs of the sick. Later their journeys were aided by two donkeys. To express gratitude for what had been done for the sick, the sisters were given gifts, usually a live chicken or a pumpkin. Sister Rita exercised her quite extraordinary healing powers so successfully, that she was much sought after from near and far. The extracting of teeth became her specialty. Soon a four roomed clinic was built on the mission. From these modest beginnings the present St Rita's Hospital developed. Today it is a training hospital for Diploma in General nursing and Midwifery. It can accommodate up to 400 patients.

St. Rita's Hospital was officially handed over to Lebowa government in 1977; currently it provides about 38 services.

3.3. RESEARCH DESIGN

This research is exploratory in nature as it attempts to explore the perceptions and experience of professionals regarding the psychosocial impact of HIV/AIDS on families. Their subjective perceptions formed the core data of the study; hence it needed the method that would deal with the topic in an exploratory nature.

For the purpose of this study, the research method that was followed is of qualitative nature using semi-structured interviews as discussed later in the chapter. Glesne (1999) explains that qualitative research is based on the belief that first-hand experience provides the most meaningful data. It is also believed that qualitative data gives large volumes of quality data from a limited number of people. It is aimed at understanding the world of participants from their frame of reference (Denzin & Lyconlyn, 1994; Potter, 2003). Qualitative research methods are tools used in understanding and describing the world of human experience. It is interpretive in nature because it gives us a way to gain insight through discovering meanings by exploring the richness, depth and complexity of phenomena (Burns & Grove, 1997).

3.4. PARTICIPANTS

Participants comprised of six health and social services professionals. Six members were selected using a non- probability purposive sampling.

There was some inclusion criteria used for participation in the study, those included:

- Participants had to be African in their race.
- They had to have had a service record of about 8 years in the area of GaSekhukhune, specifically around Nebo area at this stage the researcher assumed that participants knew the communities very well.
- Their place of origin had to be Limpopo.
- Participants had to be those working in St Ritas Hospital and that they worked directly with individuals infected and families affected.

The purposive sampling method is based on some predestined characteristics where the researcher selected the sample subjectively was based on his or her characteristics (Neuman, 2000; Bowen, 1997).The sample selection was aimed to ensure that the spectrum of respondents is representative of the Nebo population. The researcher used the above mentioned criteria during the selection of participants because participants had to be those who knew the surrounding communities well enough to provide rich information. Given the sensitivity surrounding HIV & AIDS, it was not easy to have open processes with direct families so the focus of this was on key informants.

A convenient sample of six health care and social services professionals from Saint Rita's hospital consisting of three nurses. Two social workers working directly with the affected families with respect to issuing of grants and funeral costs for families who cannot bury their deceased family members or families that might have HIV/AIDS related problems were also part of the study and a psychologist who get referrals from the nurses and social workers was also part of the sample because of the understanding of the psychological effects of the epidemic on individuals. Participants were eligible to

participate if they conformed to the following: understand the concepts HIV/AIDS were in direct contact with family members affected or infected by HIV/AIDS in Limpopo at GaSekhukhune in Nebo region, understood the cultural definition of family and the beliefs. To avoid the study to be gender biased two of the nurses were females, as well as a female social worker and psychologist, and the other nurse and social worker were males.

According to Netter (2001) (eds), the focus of qualitative researcher is more on the selected participant's ability to clarify and deepen the understanding of social life than its representatives. He further indicated that the qualitative researcher should be concerned with obtaining cases that can enhance his learning process about social life in a specific context, and that is the reason why they tend to use a non-probability sampling method. In non-probability sampling, subjects are chosen according to their relevance to the research topic because the aim is to gain a deeper understanding than to generalize to a larger population Burns and Grove (1997) describes purposive non-probability sampling as making use of experts who work with subjects to get cases which are informative. The researcher recruited the participants through the help of the hospital superintendent.

The ages of participants ranged from 35 to 49 years. Three of these participants were married and two of them were single.

3.5. INSTRUMENT

For the purpose of the study, the researcher used semi-structured interview schedules, (See Appendix D) which involved open-ended questions. In addition to the open-ended questions, closed-ended questions were used to obtain demographic data of the participants

The first section of the interviews schedule covered the biographical information of participants as well as their background pertaining to history. The second section

explored the psychosocial impact of HIV/AIDS on the families they deal with as health professionals.

The main method of the data collection used was a semi-structured interview with each participant. Individual interviews were ideal because they permit the collection of somewhat more complex data than can be obtained by questionnaire, techniques such as filter questions and elaborate skip patterns in which only some follow up questions may be asked and others skipped depending on the participants response to earlier items. In the interview situation, the researcher could explain the meaning of items if necessary and could probe to clarify ambiguous replies. Interviews also tend to yield more complete information than do self-administered questionnaires (Feldman & Johnson, 1986). Hence since this study was exploratory a semi-structured interview allowed the researcher some flexibility in the way she worded the questions for each individual participant.

Feldman and Johnson (1986) further state that the presence of the interviewer seemed to discourage refusals to provide answers to the more threatening items that might have been skipped by the respondent completing a self-administered questionnaire. Furthermore, the interview permitted the researcher to establish rapport and the permissive atmosphere, which was necessary for inducing participants to provide sensitive information. Among the disadvantages generally attributed to the interviews as compared to the self-administered questioners are the great cost, reduced anonymity and the potentially biasing effects of the interviewer's characteristics or behavior.

3.6. PROCEDURE

The researcher gained permission from the hospital superintendent to conduct the research and to interview potential participants. The superintendent was further requested to identify possible participants for this study. Letters as well as information sheets explaining the aim of the study were issued out. Permission of the participants was then sought individually. On two occasions two of the participants identified by the hospital

superintendent reported that they were busy and they could not be able to take part in the study. The researcher asked them to identify possible participants and they did so.

On meeting participants, a briefing session was held with each participant for an opportunity to get to know the participant and clarify misunderstandings. Information sheets were issued. Participants were also given consent form that they signed and the forms were written in English. In about a weeks' time the researcher held one hour-long interview with two participants separately on each day in one of the rooms provided by the hospital.

The interview sessions of all participants were recorded, using a tape recorder. This also had a separate consent forms that was signed by participants. All interviews were conducted by the researcher since according to (Morgan 1999 in van Dyk, 2005). HIV/AIDS is a very insensitive topic which needs a skilled interviewer who has ability for empathic understanding and who could listen with greater sensitivity towards. Two of the interviews were conducted in the office provided by the hospital superintendent in the hospital setting. Some interviews were conducted in the participant's offices as those provided offices were convenient for them. Some interviews took about 45 minutes and some lasted for about 60 minutes.

3.7. DATA ANALYSIS METHOD

3.7.1. Preview

It is difficult to specify when analysis really starts in a qualitative study. Therefore, this section is linked with the data collection stage (Burns & Grove, 1997). Whilst transcribing the tapes, the researcher noted that the tone of the voice sounded accusatory or skeptical in certain interview questions, this sensitized the researcher, according to Glesne (1999), to a need not to be judgmental and empathic. The researcher transcribed the tapes word-for word, denoting emotions, silence etc., with capital letters, exclamation marks and dots. Using Miles and Huberman's (1994) suggestions, the texts were then

translated from Sesotho into English. The researcher then corrected any obvious discrepancies, then read and reread the transcripts again and listened to the tapes again in order to as overfamiliarise with data, including non verbal communication (Carney 1972 ; Krippendorff, 1980).

3.7.2. Content Analysis

Theoretically-oriented qualitative content analysis was used to analyze data because a theoretical framework was a norm standard chosen for this study to categorize, analyze and compare data before conclusions could be reached. It also has an advantage of acting as a general frame of reference and thus yielding similarities, omissions and insights that would otherwise not have been thought of. It is an impartial, objective way of bringing the unexpected from the data. It also allows complex analysis, which would not been conceived of to be done (Carney, 1972; Krippendorff, 1980).

Content analysis has been defined as a systematic, replicable technique for compressing many words or text into fewer content categories based on explicit rules of coding. Content analysis began to emerge as a method of early in the twentieth century as a set of procedures designed to analyze documents. This form of analysis was in response to the need during the Second World War, to identify ideologies and propaganda in the media. It has since spread to span the areas of psychological research, especially clinical practice to focus on the analysis of interviews (Potter, 2003).

Since the stages build on each other, and overlap, care was taken not to omit or distort relevant information, as it would have seriously affected the next stages (Carney, 1972; Krippendorff, 1980; Miles & Hurbeman, 1994). The researcher reduced the data by coding, revealing these. The themes were counted to check if the phenomenon is being mentioned often or rarely. In- depth knowledge of the subject enabled the researcher to see what would have been missed, what was being emphasized the most and least. The researcher then began to look for patterns, then went deeper than mere counting of obvious themes and did in-depth analysis of emphasis. To avoid going in circles, a theme

had to fall into only one category, poor categorization would have resulted in a lot of themes falling into a ‘waste-bag’ category. Attempts were made to minimize this coding inevitably (Carney, 1972).

3.7.3. The validity and reliability of content analysis

Being a scientific instrument, content analysis has to have high and validity. This is how these were insured. Reliability refers to the extent to which a chosen measure is consistent and reproducible (Rosenthal & Rosnow, 1991). The researcher insured that she was objective, consistent as well as systematic in coding, inferring as well as analyzing data. Questions were highly operationalized so that others could reach the same conclusion (Carney, 1972). This is known as auditability, and helps to enhance the credibility of qualitative research (Burns, & Grove, 1997). The Dictaphone also enhances reliability.

Validity: To be valid, content analysis results have to be comparable to external norms. The context has to remain non-manipulated by the researcher during interviews. Being clear about one’s focus also ensured that the researcher analyzed what was to be analyzed (Bowen, 1997). With high validity i.e. (‘content-analyzing’) what is to be analyzed, it would have been easier for the researcher to know when content analysis had to be completed (Carney, 1972). But as qualitative research is always emergent, reality proved otherwise.

3.8. ETHICAL ISSUES

The following are ethical precautions taken during the study based on the researcher’s ethics proposal which was approved by the University of the Witwatersrand’s ethics Committee for this study. The purpose of the study was explained to participants verbally and they were also given information sheets (Appendix B) with the stated purpose of the study and procedures to be followed in collecting the data. It was stated very clearly that the aim of the study was to get their opinion about the psychosocial impact of HIV/AIDS

families they come across in their profession which also explained the purpose of the study. Verbal permission to conduct the study was sought from the superintendent of St. Rita's hospital and the chief professional nurse who was in charge of the wards from which the nurses were sampled.

Informed consent from all participants was obtained (refer to Appendix C) and participants were assured of their confidentiality, privacy and that their participation was voluntary. They were made aware that they were free to withdraw from the study at any point if they wished to do so without any negative consequence.

Consent to tape recording was also obtained and it was explained that the tapes will be destroyed on completion of the study. Participants were informed that the findings of the study would be kept in the University library and would also be made available to the hospital.

3.9. CONCLUSION

This chapter focused on the methodology that was used in this study. An explanation of qualitative research as a method for data collection and analysis was given. Measures followed during the data collection were discussed in this chapter and the information about the sample was provided. The research method as well as the instrument used was also discussed. The procedure for conducting interviews and data analysis techniques used preceded the final section which described the ethical considerations that informed how these procedures were carried out so that the participants were safeguarded.

CHAPTER 4

RESULTS AND DISCUSSIONS

4.1. INTRODUCTION

This chapter presents the findings of the study. The results are discussed in accordance with the themes that were identified around the issues discussed in the literature review, which were guided by the research questions. Quotes from the interview transcripts are used to substantiate these themes and the energizing themes are compared with the findings of previous studies. These themes that were identified in this study were compared with other studies. The main themes that were identified in this will be discussed around the following issues: HIV/AIDS and Poverty, impact of HIV/AIDS, understanding of a family, psychological Impact of HIV/AIDS, lack of education on HIV/AIDS, long and short term impact of HIV/AIDS, acceptance and Support

4.2. HIV/AIDS AND POVERTY

The majority of respondents expressed their concerns around poverty and HIV/AIDS. They also expressed that HIV/ AIDS was still a sensitive issue, especially in rural areas. The understanding of poverty seemed to be more on the causal perspective. It seemed like the concern was more on the cause rather than on the results.

4.2.1. Poverty Increase

Poverty increase was common in most of the responses; the following statements provide examples of different ways of how HIV/AIDS is viewed as impacting on poverty increase:

“HIV/AIDS have brought a major change in society; change in terms of economy, there is a lot of poverty. The government spends a lot of money on campaigns as well as ARVs instead of using it on families, which are poverty stricken.

“Okay if somebody is a breadwinner and is HIV infected, it will affect the family. What if he losses his job, all the things they used to get when he was still working, they won’t get them.”

“ Most breadwinners would be dead, there would be poverty, which will lead to malnutrition.”

The above responses support the fact that HIV/AIDS is perceived as causing an increase in poverty because it impacts and undermines the rights of the children. It leads to financial constrains and income impoverishment. After the parents have died, the older children now have to take the role of parents, take care of other siblings. It is clear that HIV/AIDS exacerbates poverty and the reverse. Families become poorer a result of the illness and death of members and in many cases breadwinners are the ones who die. The availability of food is a right to humanity, the need of which no other replacements can satisfy. The death of the main breadwinner has immediate financial implications. First of all, the funeral is an important ritual in African culture and it is usually quite a special occasion where all family members are expected to attend. It also has very specific financial implications and may place a large burden on the remaining family. Levers (2006) support the fact poverty and HIV/AIDS are related. The impact of poverty on HIV/AIDS is considered most catastrophic at the household level. The first respondent from the above quoted responses mentioned the fact that the blame must be put o the government for wasting money on ARVs than on prevention campaigns.

The following respondent is of the opinion that lack of jobs cause an increase in poverty and that an increase in poverty results in risky behaviours that could lead them into contracting HIV/AIDS more especially women. The government has come up with social grants whereby women are allowed to have as many children as they want in hope of

getting money. The following respondent is of the opinion that. However, this could be linked to the rate of poverty and illiteracy. People are not being educated enough as a result they get involved in risky behaviours. This mentioned statement could be debated because, what else can these people who are drowning in poverty do besides putting themselves at high risk of HIV infection. Some women and young girls who are poverty stricken end up selling their bodies just to get something to eat. The government's intention of legalizing sex work was to alleviate the rate of HIV/AIDS infection not to put people at risk of the infection and people used that to their advantage, especially those who live in poverty.

“.....Poverty, nowadays there are no jobs, so in order to get something to eat they engage in sex, especially people from rural areas.”

4.2.2. Poverty and Health Care

Half of the respondents felt that health care access to and poverty is related and one affects the other. The following responses are of the opinion that poverty is a contextual factor associated with all health related issues in Sub-Saharan Africa and cannot be ignored in relationship to the HIV/AIDS epidemic

“It affects all family members because they spend the money to pay Sangomas to heal their sick or to make some rituals to solve the problem of the person. All relatives will help with the payments, which will leave them without money as well as domestic animals such as cattle, sheep and goats because they are also or given to the Sangoma.”

It affects all family members because they spent the money to pay ‘sangomas’ to heal their sick or to make some rituals to solve the problem of the person whom they don’t know the problem at all. The relatives will help with the payments and even domestic animals such as cattle, sheep and goat.

From the above responses, not only does HIV/AIDS affect the nuclear family, but it also affects the extended family members because they form part of the family.

It is clear that people's lack of understanding of HIV/AIDS leads them to overspending their money by taking the infected or rather the sick person to a sangoma because most people in rural areas still believe that HIV/AIDS is the result of witchcraft. Then people would spend all their money and livestock paying sangomas and at the end they end up with nothing. It may result in a very sad situation whereby they have not only lost their loved ones but they have also lost their source of income and then they are left with nothing but poverty. Dakar (2003) mention that the advantages of visiting traditional healing are numerous. Faith healing has gained credence in South Africa today making the sangomas a key source of medical help to about 70 percent of the population. The sangomas or inyangas have mastered the psychology of understanding the patients, a factor which even physicians acknowledge, they sooth the patients with kind words which are not expected in some of the hospitals.

“Most people are not working, no money, they don't have money to come to the clinic. After a person has been tested, they come for checkup. So most people don't have money for transport to come for treatment so they would rather visit ‘sangomas’.”

The above quotation does not see ‘sangomas’ as obstacle to HIV/AIDS treatment but as an alternative form of treatment for people who cannot access western health care services. Some patients especially those in rural areas become so desperate and because of lack of resources, they visit sangomas. They believe that they have been bewitched and this hinders diagnosis and treatment of the AIDS patients. To many African communities the superstitions and belief in the evil spirits remains common. Traditional beliefs seem to be more appealing today in the wake of the mysteries of the pandemic. People have to come to terms with the pandemic and therefore they consult the world of spirits though at times blindly. The rural areas are more affected by this. Sangomas far outnumber western-style doctors in Southern Africa and they are consulted first by approximately

80% the population. Whilst for many they provide healing needed, there are some causes for concern, especially regarding HIV/AIDS (Dakar, 2003; Ritchter, 2003).

The above is supported by Kline (1992) that poor people are more often sick than they are better off. Their general levels of health and well being are being lowered. They are more likely to live and work in hazardous environment. They have less food and less access to clean water, their housing offers less protection from the weather and are more likely to be overcrowded. They have less access to health care and the services they have are low in quality and do not respond to their needs. They are less likely to recover completely from illness. In addition they are likely to fall even deeper into poverty as a result of working time lost to ill health and the cost of health care. Poor communities and less educated are more likely to have physically demanding jobs, yet they are less physically fit and malnutrition undermines their strength to walk to clinics.

Again it was clear from the intensity of the emotions regarding the responses that health care workers really felt overwhelmed. They themselves have fears that they might get infected. One other thing that was mentioned was the fact that they themselves become marginalized, people tend to assume that because they work with PLWHA, and they themselves are also infected.

4.3. IMPACT ON AFFECTED OTHERS

4.3.1. Impact on Children

Children were considered to be the most affected victims of HIV/AIDS because of their vulnerability. This is supported by the following responses:

“This thing also affects children, they don’t perform well at school and they can’t speak to anyone about their parent’s illness due to stigma.”

“Many people would be dead, there will be too many orphans and a lot of poverty, children won’t go to school because with this welfare people get money for 12 months only and there won’t be jobs for these orphans”.

“When we look at orphans, they get a social grant and when they are sent to live with relatives, the uncles and aunts misuse the money. There was a family of six children and the uncle did not the care worker, so no one was taking care of the children, the granny was too old and she couldn’t walk. The uncle misused the money and did not invest anything for the children.”

Most of the respondents felt that the impact of this pandemic is mostly felt at the heart of children because once parents die, they are forced to be relocated to other extended family members, they are forced to drop from school and sometimes it occurs that they quit in the middle of the year. At times it happens that even those extended family members are so poor, so the older child will have to see it that he leaves school, looks for a job so that he can be able to care for his siblings. Children become very vulnerable and would do anything just to survive, so would exchange money for sex and in turn get infected. So in this way the circle of the infection continues. Sometimes these children are forced to drop out of school because they have to look after their siblings or sometimes have to go and look for jobs. Coombe (2000) state that as HIV/AIDS reduces the number of parents 20 to 40 years old, numbers of orphaned children increase, poverty depends, school enrolment rates are expected to decline. Dropouts due to poverty, illness, lack of motivation and trauma are set to increase. There is also absenteeism among children who are heads of households, those who help to supplement family income and those who are ill.

According to Lyons (2000), poverty is clearly a factor in the spread and impact of HIV/AIDS. The struggle to survive everyday overshadows attention and concern about a virus that does not demonstrate any immediate harm. Poverty pushes families, often unaware of the risks, to send children into the workforce. The illness or death of parents or guardians because of HIV/AIDS can rob children of their emotional and physical support.

It leaves a void where parents once provide love, protection and support. Instead of receiving special care and assistance, childhood is spent providing care and assistance.

UNICEF (2003) supports this by stating that 14 million children under the age of 15 have lost one or both parents to AIDS. By 2010, this number is expected to exceed 25 million. With global infection rates rising, HIV/AIDS will continue to cause suffering among children for at least the next two decades if not longer. It takes roughly 10 years between HIV infection and death from AIDS, so today's prevalence levels will largely determine the number of orphans over the next decade. Because of the lag or time between infected and death, the number of orphans will continue to increase even in countries where infection rates have declined.

Psychologically, it is not an easy situation for children. The child goes to school, meets other children who are happy from their home and the child becomes retraumatized because they see how happy other children are, they have no one to talk to because parents are both dead. However with the government today children are now able to have foster parents or rather to get a social grant, but some of these foster parents do it for the love of money and instead of using that money to meet the needs to the children they use it for their own benefits so at the end these children's needs become compromised and sometimes the child's emotional needs are neglected. Sometimes these children become exploited by the extended family, they are not taken to school and if it is a girl, she would have to do all the household chores.

These children will live in poverty and they end up running away ending up as street children, little girls would exchange money with sex in order to survive and in turn be infected with HIV/AIDS.

4.3.2. Impact on Women

The following responses indicate how women could at times be marginalized by the cultural beliefs that some communities still hold. As a result women's independence is

compromised by these cultural beliefs. Issues around polygamy definitely put woman at risk of being HIV/AIDS infected. If a man decides to marry another wife, normally the first wife does not have a choice but to agree to whatever the husband tells her. Even when it comes to the usage of condoms, women are the once who often initiate that and sometimes they become scared to initiate the because of fear of accusations around mistrust.

“Another thing men oppress women. Like women do not have freedom of choice. They must do everything men tell them to do; they do not initiate use of condoms. Okay and then now “In our culture men marry too many women, even women do not have a choice if he decides to marry another wife he can do it. That is how AIDS is spread.”

“If I marry your sister and I’m infected and you don’t know that, then I decide to marry another woman, that poor woman would be infected.”

The following response the fact that migration also puts women who are left back at home in rural areas, at risk of being infected by their partners. These partners are forced by poverty to migrate to urban areas. When they get to urban areas these individuals are subject to poor living conditions and loneliness. These men then cheat on their wives, from the following response it is evident that these men are illiterate and do not believe in the fact that they could get infected by the virus. As a result they get infected and when they go back to their rural wives they also infect them.

“The other thing is that most husbands go to the cities to work and when they get there they meet other women, maybe prostitutes; then get infected and infect his wife he left at home. Poor innocent women die because of unfaithful men who are illiterate and don’t believe that HIV/AIDS exist.”

4.4. PSYCHOLOGICAL IMPACT OF HIV/AIDS

The Majority of respondents felt that HIV/AIDS cause change in family relationships and a few emotions were picked out in relation to the psychosocial impact on families and these feelings range from fear, denial, isolation, stigmatization, discrimination, conflict and rejection.

“There will be conflict in the family with regard to caring for that person when he is terminally ill. There is also discrimination, they isolate the person who is infected, and they do not want to share things like spoon with that person.”

One respondent felt that families themselves discriminate against members; they fear that by caring for the terminally ill person they will also get infected as results they tend to neglect the person or rather fight amongst each other. On the other hand the infected person feels unsupported and rejected and isolates themselves due to the stigma associated with HIV/AIDS, that if you are infected you are perceived as being ‘contaminated’ The respondents felt that sometimes families deny the reality of HIV/AIDS and would consult ‘sangomas’ for reassurance. However, at the back of their minds they know reality but are scared to confront it and disclose the status because of fear of how other community members are going to take it, this is a protective tool for the family.

“People don’t accept..... they are in denial (laughing), people think that they are going to die, if they are HIV positive. People discriminate the person who is HIV positive, they don’t want to help the person, especially when terminally ill, they do not get support, and very few people get it.”

One other thing that came up was the stigmatization came up as an issue that is causing concern; people out of fear choose not to disclose their status. They would rather spend a lot of money in trying to understand what is happening with them, for example like visiting ‘sangomas’. At times people choose not disclose as a way of protecting

themselves from discrimination and the possibility of physical violence. HIV/AIDS has often been considered a form of punishment for wrongdoing and associated with promiscuity and witchcraft.

According to the HelpAge International HIV/AIDS Alliance (2003) this can result in acute levels of exclusion. Social ties and traditional support mechanisms can be weakened when ignorance and stigma marginalize a family affected by HIV/AIDS leaving them feeling ashamed and alone. The trauma from the loss of family members and the stigma of being affected by HIV/AIDS can result in high levels of exclusion for older people or leaving them feeling ashamed and alone. Many older people feel they are failing in their role as caregivers because they are unable to protect their family from social isolation. Alongside the stigma and exclusion, orphans and vulnerable children and their older caregivers experience grief and possible confusion following the loss of their parent, child or in many cases multiple family members. Older people often play an important role in comforting young children on the death of their parents and in providing support and guidance. Yet the older people themselves are under pressure with psychological problems of their own following the death of their children. Grief, loss, anger, fear and the worry of bringing up orphaned children who may be HIV positive.

True World AIDS day report (2005) states that from the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS. It goes without saying that HIV and AIDS are as much about social phenomenon as they are about biological and medical concerns. Across the world the global epidemic of HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. But the disease is also associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer counties.

Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. ‘homosexuals, injecting drug users and sex workers’) may predate HIV/AIDS, the disease has, in many cases, reinforced this stigma. By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations. This is seen not only in the manner in which ‘outsider’ groups are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need.

4.5. UNDERSTANDING OF A FAMILY

There were various understandings from the respondents of what a family is. Some understood it as a being nuclear, some communal.

4.5.1. Nuclear Family

“A family in my culture. It comprises of all my family members that is my brothers, sisters, uncles, their children, their grandchildren, the in-laws and not forgetting my grandparents from both paternal and maternal family.”

The respondent’s definition almost fit with Goldenberg’s (2000) definition of a family, whereby it is seen as a collection of individuals sharing a specific physical and psychological space and is also seen as a natural social system, the relationship between members of this microculture is deep and multilayered and is based largely on a shared history, shared internalized perceptions and assumptions about the world and shared sense of purpose. Within such a system, individuals are tied to one another by powerful emotional attachments and loyalties that may fluctuate in intensity overtime but nevertheless persist over the lifetime of the family. Entrance into such an organized system occurs through birth, adoption or marriage. When we look at the cultural definition of the respondents even though they have only given the structural definition of

what a family is, one gets a sense that their definition ties in with above mentioned definition, whereby it also mentions the emotional attachments and well as loyalties. The two respondents below describe a family as a nuclear system.

Interestingly, the above-mentioned respondent did not include parents so one can speculate that in her culture it is assumed that automatically parents form part of the family.

“A family is all about respect; it is about two married people and their relatives.”

One respondent brought in some emotional meaning of what a family is all about. The following respondent felt that a family is about respect, if there is no respect then there is no family. If we look at HIV/AIDS and its impact on the family, one of the major issues is around stigma in the family itself. So surely if there is stigma then it means that the level of respect amongst family members decrease, therefore this changes the whole definition of the family.

4.5.2. Communal Family

Not only was a family seen as a nuclear system but also seen as a system that is extending beyond nuclear, that is, community viewed as a family system. The following respondent describes it as:

“A structure that is normally made up of both adults and youth living together. Often it is parents living together with children.....it also mean a sense of belonging, which defines an individual’s position and role within the community. E.g., any adult male within the community holds a role of being a father to all individuals younger than him (children). Likewise youth hold a role of being children.”

“Anyone older than me in our village is my parent; I do have my own family that is my parent, sisters, brothers and grandparents as well as my extended family. But let’s say

maybe the chief has got something to say to us, he regards us a family when he addresses us, so everyone in our community is a family”.

This definition supports Macklin’s (1989) statement that a family as a system constitutes of subsystems. A family as a system has elements whose sum forms a whole; therefore each member has their role in the family. However, the impact of HIV/AIDS causes change in the family structure and the roles of each member of the family as well as the need for redefining the composition of the family. Another respondent defined the community as a family, which is a macro system as a family. If this is the case then this may play to the advantage of HIV/AIDS impacted families because if then, the definition of what a family is forced to be redefined. If the community or rather every elderly person in the community is seen as a parent then this would make it easier for people to be able to access the support they need not only from their family members but also from ordinary members of the community. The above mentioned seem to be for and against Barolsky (2003) understanding of the impact of HIV/AIDS on families.

The research indicates that the effect of HIV/AIDS on families is profoundly dependent on prior relationships. If families whose bonds were strong before a member becomes HIV positive, emotional resources and networks of care are activated and often strengthened by the new challenge HIV presents. However, if a family was already in a state of collapse or tension, the burden of HIV can impact heavily on the balance of power and interaction, causing some families to reject and exclude those who are infected and their illness may bring a threat to maintained family cohesion, breaking up bonds held by the family. Heath (2000) state that this may cause the family to move from being a nuclear family to an extended family or rather communal family.

4.6. LACK OF HEALTH EDUCATION

Some respondents felt that lack of education is a major contributor to the spread of HIV/AIDS. It is evident that a lot still need to be done pertaining to HIV/AIDS education

and more specifically in rural areas. Some of the responses that they gave to support this argument are the following:

“Lack of information, people are not educated about this. They are in denial. I remember the health talk we had in OPD; this man said he was too old and shouted at us for telling him to use condoms whereas we are so young.”

“Lack of education because they think is the end of the world.”

Some people do not that believe HIV/AIDS exists unless they have seen someone within their family, friends or neighbours been infected. Some are scared to test as they believe that knowing one's HIV-positive status can bring about death sooner than expected in terms of stress, denial of accepting the condition and lack of support by loved ones. Illiterate people (especially in rural areas) think that talking about HIV/AIDS is for 'educated 'people'. Lack of education about HIV/AIDS in the community level result in lack of support from the family as well as from the community as a whole. Even amongst the elderly people who take care of orphaned children, a lot of education is still needed.

According to Heath (2000), one of the major issues in South Africa is educating the public about the modes of infection and prevention and dispelling misconceptions about HIV/AIDS. For those who live in the rural areas, there is little formal education and limited access to information. AIDS has been difficult to comprehend and conceptualize, with the onset of symptoms arriving years after infection. Health researchers and educators have encountered difficulties in facilitating an understanding of the severity of such an abstract disease as HIV/AIDS among the African population. Illiteracy is a problem and most people in rural areas are not educated especially elderly people who have to take care of their ill children. Nicholson (2002) also realizes that illiteracy is a serious handicap, which condemns people to a life of poverty, low self-esteem, and unemployment and boredom.

Many youth in rural areas drop out of school due to poverty and as time goes on they turn to crime. Crime is their only source of income for food and basic needs. Literacy, access to information and education are the key essentials to self-development, self-dignity and a better life. Nicholson (2002). Nicholson, (2002) further states that South Africa has two very different dimensions – First World and Third World. In the First World dimension there is wealth and a highly sophisticated infrastructure with digital and other advanced technologies, which can be compared with most developed countries around the world. However, in large sections of the country, the Third World dimension is very evident in rural areas and informal settlements around urban areas. The situation is one of dire poverty, high illiteracy and unemployment, and poor economic prospects. Most rural people do not have access to the printed media, let alone digital technology. Inability to access information is a major problem and is widening the gap between the ‘haves’ and the ‘have-nots’.

Most illiterate people or functionally-illiterate people have grown up in a rural community, not always by choice though, because of pre-1994 Apartheid land laws which forced people to live in certain rural areas. They live far from urban areas and are mostly involved in subsistence farming. There is little or no road infrastructure and access to these areas can be extremely difficult. As a result of poor education and other factors, deforestation, overgrazing and improper farming are threatening the soils and other natural resources which are critical to their livelihood and for the general prosperity of the region as a whole. Their homes are tin shacks, mud huts or outbuildings on someone else’s land. Few people have water services, electricity; refuse removal services or telephone lines. Traditionally, and for obvious reasons, oral communication is the main form of communication. Information is shared and spread from one person to another, in one or more of the 11 South African official languages. For those employed, their means of transport to work is generally by foot or by bicycle, if they are privileged to own the latter. Their children walk many kilometers to and from school each day.

Nicholson (2002) further mentions that most schools are makeshift buildings, which are mainly structures of brick and tin, with few or no windows and doors. Some schools have

lessons out in the open or in homes, as there are no classrooms. There is no electricity or running water. Natural lighting is often the only source of light and on cloudy days their ‘make-do’ classrooms are dark and cold, making learning a difficult and unpleasant experience for scholars. School desks are made from boxes, broken chairs and tables or piles of bricks. Stationery is usually inadequate and books, magazines and other educational material for teaching and study purposes are extremely limited. Photostat material is often the only source of information. Most scholars come from seriously poverty-stricken homes where even food is a luxury and money for basic amenities is not available. Being able to purchase textbooks or other educational material is rare. Access to information is extremely difficult and these people are entirely dependent on assistance from donors, community leaders, social workers, facilitators, teachers and librarians where library services exist. Due to inadequate healthcare and prenatal care, many are also physically or mentally disabled. This exacerbates the problem of accessing information as their special needs can rarely be addressed.

Very often these communities do not have any library services and depend on basic information spread verbally or information provided at local community resource centres.

4.7. LONG TERM AND SHORT TERM IMPACT OF HIV/AIDS

4.7. 1. Increased mortality rate

Some of the participants projected that there would be increased rates of infection and as well as increased mortality rates the following responses support this:

“(Laughing), people would be dead, let me estimate, youth, which is half o the population would be gone. I blame us as health professionals as well as government for coming up with rights.”

“(Yoo, yo), almost 90% of the people would be dead, the rate is going high, media talks about the increase. Everyone would be infected unless we get treatment.”

The shifting patterns of mortality and increasing number of deaths due HIV/AIDS compels for a fundamental interrogation of the boundaries of life and death. The magnitude of death due to HIV/AIDS is disallowing rigid boundaries between life and death which places a great challenge on traditional rituals of death. People used to bury their loved ones over weekends, but these days it is not uncommon to find cemeteries packed with mourners during the week. With HIV/AIDS attending funerals has become a common thing and as a result some people say they can no longer be bothered to attend. Posel (2003) argues that premature, unnatural and unwarranted death is nothing new in South Africa. On the one hand, it is evident that there is a qualitative shift in who is dying. HIV/AIDS strikes young women as well as children. Barolsky (2003) argues that a number of communities' individual deaths due to HIV/AIDS are being marked as an affirmation of the possibilities and value of life, contaminated. These 'open burials as the potential of early intervention in the process of disease through disclosure as well as celebration by the public for courage of those who faced HIV/AIDS.

UNAIDS (2004) supports the above view by pointing out that HIV's impact on adult mortality is greatest on their twenties and thirties, and is proportionately larger for women than men. In low- and middle- income countries, mortality rates for 15-49 year olds living with HIV are now up to 20 times greater than death rates for people PLWHA in industrialized countries. This reflects the stark differences in access to antiretroviral therapy. In low- and middle-income countries, mortality generally varies between two and five deaths per 1000 person years for people in their teens and twenties (Porter & Zaba, 2004).

4.7.2. Changes in the Definition of Families

Majority of the respondents were of the concern that HIV/AIDS has caused some change in the structure of families as well as the family functioning.

“Possibly it will bring a different definition of families. What we presently regard as the child headed family would be regarded as normal.”

“I don’t know, there is just so much that I don’t know what to mention. It has caused so much impact. It has disrupted a sense of what a family is. Would you call a child headed household a family? We see so much of this because of HIV/AIDS, children are orphaned and they are forced to be adults before their time. They drop out of school because they have to look after their siblings. When we look at the relationship in the family, HIV/AIDS has disrupted the healthy relationship. Family members now have to worry about the ill person, the whole attention is given to them and other family members’ needs are not met.”

“ People would have stress, many people would be dead and there would be too many orphans, widows and a lot of poverty.”

“Difficult to project but one thing for sure is that there will be many families dismantled by death of the members. Possibly communities will be faced to take care of the affected families.”

From the above responses it is evident that the reality of the epidemic forces individuals to re-evaluate what is meant by family and community to question the apparently fundamental norms which have previously underpinned these institutions and to look beyond social convention to care and protect the socially vulnerable in the context of HIV/AIDS. Creating new families means reassessing questions of lineage and blood ties and seeing how these can be maintained even if family members are receiving care and support in another structure. It means looking at the possibility that young people can be socialized and old people supported by different social institutions that could be called families. The HelpAge International HIV/AIDS Alliance (2003) points out that as the HIV/AIDS epidemic strikes at the heart of family and community support structures, large numbers of older people are assuming responsibility for bringing up orphans or vulnerable children. Family structures are changing, often the middle generation both men and women is completely absent, leaving the old and the young to support each

other. This means that families of older people and young are compelled to take on new roles.

4.8. ACCEPTANCE AND SUPPORT

All the respondents felt that HIV/AIDS infected and affected people should be accepted and given the support they need. However, in real life this seems to be a difficult for people, especially those who do not understand this epidemic.

“They should love the person like they used to, HIV/AIDS is just like any other disease, example cancer. We know that there is not cure for it but we still continue supporting and caring fro the person, why cant’s we do it with HIV/AIDS”.

They must accept the positive person, support him and help him in ways that can help him cope, example going to the clinic to get help.”

Participants mentioned that their major concerns regarding families infected or affected by HIV/AIDS is that they do not get the support they need from the community. They also mentioned that even individuals who are infected do not get the support from their families and as it is well known, families are known sources of support. If an individual does not get support from the family, he or she might end up being depressed. Sometimes it is not like they do not want to give support to their loved ones, they themselves are overwhelmed by the fact that they have to care for the terminally ill person and this can be strenuous, because you are not only caring for them but also starting to mourn their loss. Participants also mentioned that because of fear of stigma and contamination, sometimes this families would hide their ill loved one, or rather built them a separate zozo, this will definitely leave the HIV positive person isolated and withdrawn.

“According to me if there is someone in the family infected, she should be accepted, supported and loved. They should not be scared to disclose so that we can stigma. If you

are aware most families have not accepted this pandemic so if families could disclose more knowledge would be added to our society.”

The above argument that due to disclosure fears and stigma associated with HIV and AIDS infection, many families isolate themselves from their extended families and communities to protect themselves and their children from maltreatment. Thus they are cut off from valuable support. In conjunction with coping with the psychological emotional issues of being infected with or affected by HIV/AIDS, these individuals are forced to deal with a multitude of stressors with little support. These factors place these individuals and their family members at risk for mental health disorders (depression, post-traumatic stress disorder and anxiety), development impairment and behavioural problems (e.g., drug or alcohol use, school failure, inability to maintain a job and criminal behaviour). According to the WHO (2005), HIV infection affects all dimensions of a person's life, psychological, social and counseling and social support can help people and their careers to cope more effectively and their quality of life can be improved. With adequate support PLWHA are able to respond adequately to the stress of being infected and are less likely to serious mental health problems.

4.9. CONCLUSION

This chapter has presented results of this study in accordance with the themes that were identified. Quotes from the interview transcripts were used to illustrate these themes and these were discussed with reference to the literature and findings of previous studies.

CHAPTER 5

SUMMARY, LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS OF THE STUDY

5.1. INTRODUCTION

The summary of the findings will be discussed with specific reference to the research question, which was based on the psychological and social impact of HIV/AIDS on rural black families, how it changes family structures as well as its impact on the relationship of individual members of the family. The researcher will also discuss the conclusions that were deducted from this study. The limitations of the study will also be looked at in this chapter, and the researcher will then discuss the clinical implications these results have for families and also for professionals working with HIV/AIDS cases, with recommendations for these families as well as health care professionals regarding interventions.

5.2. SUMMARY OF THE FINDINGS

The study used a total sample of six participants who are health care and social services professionals. These participants comprised of three nurses, one being male, two social workers with one being male and a psychologist. The main aim of the study was to investigate how HIV/AIDS impact on the psychosocial well-being of families through perceptions of the above mentioned professionals.

The interview method was the main method of data collection and therefore produced qualitative data. Interviews were carried out over a period of two weeks with the researcher visiting participants in the hospital at their convenient time and place. The data of the study was analyzed by means of thematic content analysis.

The main findings of the study in terms of the psychosocial issues of families were that HIV/AIDS is regarded as a main contributor to poverty as well as increasing the rate of poverty in these rural settings. In addition, participants felt that HIV/AIDS is changing the cultural definition of a family as well as the structural component of the family and relationships of individuals within the family.

The main concerns of health care professionals about these families were that HIV/AIDS impacts a lot on vulnerable people, specifically children and women. Children become orphans and they are left to care for their siblings or taken to extended family where they get exploited. So these children are forced to become adults and they lose their childhood so their developmental milestones as well as their mental state become impaired.

Participants also raised concerns about the fact that families experiencing the impact of HIV/AIDS are not supported psychologically. At times they themselves do not support the infected member, so they stressed the necessity of psychosocial support for these families. They linked the above mentioned to stigma; they feel that stigmatization is still a major issue that needs to be addressed in communities. They also mentioned the fact that traditional healers play a role in the increase in poverty because people spend a lot of money taking their ill loved ones to 'sangomas. It was also implicated that the very same traditional healers can offer physiological and psychological care to people who cannot access western health care services. They revealed the fact that it is important that traditional healers also get educated about the pandemic. It was also evident that education is still needed regarding issues around stigma and discrimination as well as elderly people who take care of their ill children as well as orphans. Psychosocial support was seen as being very crucial but the problem was that, some of the services needed are not accessible, for instance there might be a shortage of psychologists and social workers, nurses might be burnt out.

5.3. LIMITATIONS OF THE STUDY

Various methodological limitations have to be taken into consideration when analyzing this study. Firstly, the sample used was limited by the fact that they reflected the views and opinions of participants involved, the researcher did not interview the families directly. Thus the study cannot be generalized to HIV/AIDS infected or affected by this pandemic. This thus decreases the external validity of the results obtained.

Another limitation is that the researcher selected health care and social services professionals hoping that they would provide her with in-depth information. However, this did not turn out the way the researcher had hoped because some of the information. The researcher assumed that maybe there are differences between people working in rural areas and those working in urban areas in terms of how knowledgeable they are regarding the HIV/AIDS issue.

Despite these limitations, however, it must be added that this study yielded valuable data.

5.4. RECOMMENDATION REGARDING INTERVENTIONS FOR FAMILIES IMPACTED BY HIV/AIDS.

HIV/AIDS infected individuals and their affected families are forced to cope with a multitude of stressors. Supportive psychotherapy may be utilized to improve quality of life and address mental health disorders. Historically traditional psychotherapy and psycho educational interventions have not addressed the ethnically and culturally diverse issues pertaining HIV/AIDS. Therefore professionals must employ flexible and effective interventions that encourage HIV/AIDS infected individuals to efficient coping and management skills.

Limited information is available on the cost of providing psychosocial support for HIV/AIDS in rural poor settings. Such care is either infrequently provided, has not been documented. Basic psychosocial support can be provided by health care professionals and

incorporated into the care provided in hospitals and clinics. Accordingly, cost should not be a problem, community groups can be trained in the provision of psychosocial care such as support groups

UNICEF believes that whenever possible, children who are orphaned should remain in their communities to be raised by their extended family. Recognizing that family care is better for children and far less costly than institutionalized care, children who grow up in families also develop better social skills and are psychologically better adjusted than those who grow up in institutions because they receive more affection and attention and develop a better sense of personal identity. This is why UNICEF is working with NGOs and community groups to help ensure that families have resources they need to adequately care for orphaned children. This support ranges from providing psychological counseling and helping parents with planning, job training, paying school fees and providing basic education (UNICEF, 2003).

A very important issue to deal with in order to develop an effective response to AIDS is destigmatisation. While AIDS is treated as a scandal, is kept secret and PLWHA are discriminated against, it is very difficult to address the disease. Public education, awareness, prevention and care programmes need an atmosphere of openness to flourish. Destigmatisation is one of the biggest challenges we face tackling HIV/AIDS. As the political leadership of municipalities, counsellors have an important role to play in this. Destigmatisation can only succeed where openness is promoted and discrimination becomes the norm.

Since the researcher found out that these healthcare professionals do not get any formal psychological support, it is recommended that health care professionals should initiate counseling sessions at which they will be able to share their experiences in relation to dealing with families affected or infected by HIV/AIDS.

5.5. RECOMMENDATION FOR FUTURE RESEARCH

Based on the results that HIV/AIDS is major concern for health care and social services professionals working with families affected or infected by the pandemic. The study also indicated that traditional healers are considered as perpetuating the lack of knowledge about HIV/AIDS because most people in rural areas still believe in witchcraft. There need to be more research done regarding HIV/AIDS and rural areas so as educational programmes could be developed.

Another issue of concern is the fact that women in rural areas are still oppressed once they disclose they become victims of violence. More research needs to be done to fill the gap in knowledge that exists in these areas. Thus it is proposed that a study be designed to train healthcare professionals regarding educating the community, however participants reported that they sometimes feel overwhelmed by their job. A programme designed to support these health, mental care and social services professionals is also proposed.

Finally a similar study be conducted using a larger sample drawn from a number of hospitals in Limpopo in order to allow for generalizability of the findings which can be generalized to the whole country.

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APPENDIX A

P.O. Box 6
Glen-Cowie
1061

The hospital Superintendent

Saint Rita's' Hospital

Dear Sir

Re: CONSENT TO CONDUCT RESEARCH AT THE HOSPITAL.

I am a Masters student in Clinical Psychology at the University of Witwatersrand. As part of my degree I would be conducting a study on "Perception of health care and social services professionals on the psychosocial impact of HIV/AIDS on rural families. I am requesting your assistance in this regard and also obtaining the sample. Attached is the copy of the Ethics approval for this study from the Wits Ethics Committee.

My contact details are as above should you wish to clarify something.
I hope my letter will meet your approval.

Thanking you in advance
Yours Sincerely
Ponky Ramosolo
M2 Clinical Psychology.

Cell: 0795147574

APPENDIX B

SUBJECT INFORMATION SHEET

Hi! My name is Ponky Ramosolo and I am a Masters student in Clinical Psychology in the school of Human and Community Development at the University of the Witwatersrand. I am conducting research on the perception of health care and social services professionals on the psychosocial impact of HIV/AIDS on rural families.

I would like to ask you to participate in this study. I require approximately 45-60 minutes of your time. By doing so, I would be very grateful if you grant me permission to use your responses to my study.

Please note that your responses will be completely anonymous since you are not required to submit any identifying information. Your responses will be treated with the utmost confidentiality and will not be shown to anyone other than the researchers involved in the study. You may choose to withdraw at any stage without penalty.

Given my understanding of anonymity and confidentiality, I ask you to respond as openly and honestly as possible. Please note that I am interested in your responses, and there are no rights or wrong answers.

Please detach and keep this letter. Should you require further information, please feel free to ask. My details appear below.

Yours Sincerely

Ponky Ramosolo

0795147574

APPENDIX C

Interview Consent Form

I ----- Consent to being interviewed by Ponky Ramosolo for her study on the Perception of health care and social services professionals on the psychosocial impact of HIV/AIDS on rural families. I understand that:

- Participation in this interview is voluntary
- I may refuse to answer any question I would prefer not to.
- I may withdraw from the study at any time.
- No information that may identify me will be included in the research report and my responses will remain confidential.

Signature-----Date-----

Witness-----Date-----

APPENDIX D

Consent for Audio Tape

I -----content to my interview with Ponky Ramosolo for her study on the Perception of health care and social services professionals on the psychosocial impact of HIV/AIDS on rural black families being tape recorded. I understand that

- The tapes and the subscripts will not be seen or heard by any other person at the university at any time, and will only be processed by the researcher.
- All tape recordings will be destroyed after the research is complete.
- No identifying information will be used in the transcript or the research report.

Signed-----Date-----

APPENDIX E

Interview Sheet

Section A

1. Biographical Information

- Age
- Gender
- Position at work
- Duration of service

Section B

2. Research Questions

1. What do you understand by the psychosocial impact of HIV/AIDS?
 - (i) What social and psychological impact does HIV/AIDS?
2. How would you describe a family in your culture?
3. In your own opinion. What is the impact of HIV/AIDS on the family's psychosocial well-being?
4. What are the possible reasons associated with the impact of HIV/AIDS pandemic on families?
 - (i) Why does HIV/AIDS impact on families?
 - (ii) How does it impact on families?
5. What impact will HIV/AIDS have on communities and society as a whole in South Africa by the year 2015?
 - (i) In your own opinion do you think by 2015, there would be some development regarding HIV/AIDS in South Africa?
6. According to you what impact will HIV/AIDS have on the psychosocial well-being of families by the year 2015?
7. According to you what do you how do you think should families affected react to Experiencing the impact of HIV/AIDS.

(i) How should families treat the infected members of the family and how should individual members of the family treat on another/