

**AN ANALYSIS OF THE MENTAL HEALTH OF FAMILIES  
AFFECTED BY HIV/AIDS IN RWANDA**

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**AS A PARTIAL REQUIREMENT FOR THE DEGREE:  
MASTERS IN MENTAL HEALTH NURSING**

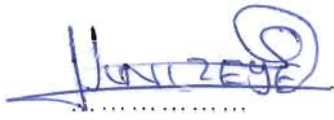
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**DECEMBER 2004**

## DECLARATION

I Glorieuse Uwizeye declare that this dissertation entitled “Analysis of the mental health of families affected by HIV/AIDS in Rwanda” is my own work and has not been submitted for any other degree or examination in other university other than University of KwaZulu-Natal. I have given complete acknowledgement to the resources referred to in this study.



Signature (G. Uwizeye)

.....

Date

## **DEDICATION**

This work is dedicated to my lovely parents for the precious initial education, inspiration and encouragement that has enabled me to reach this far.

## ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to individuals and institutions that have contributed to the realisation of this study. My special thanks to:

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## **ABSTRACT**

### **Aim:**

HIV/AIDS is no longer seen as an individual problem as it also affects the family as a whole. The purpose of this study is to purpose of analysing the mental health of family affected by HIV/AIDS in Rwanda. It should be noted that there were not studies conducted on the mental health of the affected families in Rwanda.

### **Research design:**

A qualitative approach using case study design was used to describe the mental health of affected family in Rwanda. HIV/AIDS-related stressors, emotional reactions of family members and coping strategies they adopt to deal with those stressors and emotional reactions were studied. The effects of those reactions and strategies on the infected family member as well as the entire family were analysed. A purposive sampling was used to select two families from Mwana Ukundwa Association for the study.

### **The findings:**

The findings of the study showed multiple losses, care, and socio-economic demands as the main stressors for both cases. Emotional reactions to those stressors included shock, anger, sadness, hopelessness, depression, fear and shame. Participants reported using both emotional and problem-focused coping strategies. Compassion, caring and showing concern had positive effects on the infected and affected as well as family members, whereas emotional reactions such as anger, unhappiness, and discouragement had negative effects on the entire family. Positive effects of family reactions and strategies to cope were associated with coping strategies such as; having opportunity to talk to someone, distraction, family relationships, spiritual support, treatment, and

socio-economic support. Ineffective strategies included family communication dysfunction due to withdrawal behaviour, alcohol abuse and going to nightclubs. These strategies had negative effects on both infected and affected family members.

**Recommendations:**

The results suggest that health professionals such as nurses, doctors and other health-care providers should use a holistic approach in caring for infected family members. They should not only provided family care, but also include the family in planning to care for the infected family member. This will empower them to play a more effective role in home care-based.

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# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 Background to the problem**

Since the first reports of American gay men dying of Pneumocystis Carinii Pneumonia in the early 1980s, Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) has had an impact on individuals, families and societies throughout the world (Taylor, 2001). Despite the efforts made, there is still no vaccine or cure for this virus. The virus continues to claim lives of children as well as adults.

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) the number of people living with HIV continues to increase from 35 million in 2001 to 38 million in 2003. Sub-Saharan Africa continues to be the most affected region of the world (UNAIDS, 2004). Rwanda, a Sub-Saharan country, is counted amongst nine African countries most severely affected by HIV and AIDS. Approximately 13.5% of the Rwandan population live with HIV/AIDS; the majority of which are aged between 25 and 44 years (Commission Nationale de Lutte contre le SIDA au Rwanda, 2004).

AIDS related infections are one of three leading causes of death in Rwanda. It was estimated that at the end of 2001 there were 260,000 children orphaned by AIDS. The mortality rate has increased in all age groups due to AIDS related infections and it is expected that the life expectancy will drop to 32 years by 2010 (USAID, 2004). It is evident that the number of HIV infected people in Rwanda has increased. As a result, the number of families affected with HIV/AIDS has increased.

In the beginning, the infection was seen as a medical problem. Intervention was mainly concerned with those infected, while those who were affected seemed to be less considered (Lesar & Maldonado, 1997). The Joint United Nations Programme on HIV/AIDS (2001a) states that individuals living with HIV/AIDS are not isolated; they belong to institutions that are affected by their illness and death. The family is the institution that is most adversely affected by HIV/AIDS. HIV infection has tragic effects such as psychological, extraordinary care, and socio-economic demands that; not only affect the infected person but also his/her family and even on the community as a whole (Lesar & Maldonado, 1997). Traditionally, a family is considered to be the primary source of care, because of the major role it plays in caring for the infected family member (Ried, 1997).

Since the diagnosis of HIV, the infected person as well as other family members who are aware of his/her status, starts to anticipate the loss of health and impending death (Van Dyk, 2001). The diagnosis of a chronic illness of a family member is considered as the most feared threat to that family. Van Dyk (2001) argued that such a life threatening condition induces emotional reaction analogues to those related to the loss of loved one, for both the infected family member and his/her family.

As the infection progresses to the AIDS stage when the infected person develops symptoms and becomes too weak to take care of himself/herself the family is called to play a major role in his/her care (Jackson, 2002). The family helps with all the physical demands of the illness from bathing the infected person, preparing meals to assisting in medication and staying with the patient. In addition, the family is expected to provide emotional support (McKenry & Price, 1994). Most members of HIV-affected families may find themselves under intolerable care demands and burnout as their role is extended (Jackson, 2002).

Steinberg, Johnson, Schierhout and Ndegwa (2002) state that taking care of a HIV/AIDS infected persons has not only had emotional effects on family members, but also has a major affect on family resources. The family expenditures for medication increase. In addition to that, some family members have to take time off work and income-generating activities. The sick member might be the one of the contributors to the family finances or perhaps the main breadwinner. It becomes complicated for families because in addition to the HIV/AIDS issue, they also live in poverty. This may be the case for most affected families in a country like Rwanda (McKnerly & Price, 1994; The United States Agency for International Development [USAID], 2004).

HIV/AIDS affects all aspects of family life. The family experiences a disruption in their normal social interaction both within and outside the family (Lesar & Maldonado, 1997). Health care regimens are time consuming and rigorous, which prove taxing to all family members (Melnik, Moldenhouer, Feinstein & Small, 2001). The family attention is directed to the infected family member while the rest of the family members seem to be forgotten (McKenry & Price, 1994). Family social activities are also forgotten. In addition, the stigma associated with HIV/AIDS leads to secrecy around the infection, even between family members. As a result, there is little or no communication within the family. Care demands, as well as stigma related to HIV/AIDS may result in disruption in the family interaction with significant others (UNAIDS, 2002b).

Clearly, such multiple losses, especially the anticipated loss of a loved one, care and socio-economic demands that the affected family goes through; may be seen as family stressors.

These stressors affect the mental health of family members. Such situations trigger a range of emotional reactions such as shock, denial, anger, guilt, self-blame and blaming others, chronic sorrow, depression, fear and anxiety and acceptance (Kaplan & Sadock, 1998; Van Dyk, 2001). Though these are known as normal reactions to any life threatening condition/disease (Van Dyk, 2001), in some cases, they might precipitate mental illness.

Studies reported some coping strategies that are used by HIV/AIDS affected families. In a study conducted in United States of America amongst African American women living with HIV/AIDS, it was found that family members pull themselves together to support the infected family member (Owens, 2003). Other families strive to normalize their situation by using consistent and creative strategies to incorporate the HIV related issues into their daily routine (Beverley, Lilian, Salter, Dale, King, & Susan, 2001). Lesar and Maldonado (1997) found that affected families strengthen their relationships within as well as outside the family in order to cope with psychological effects of HIV/AIDS. Social isolation was also reported as a coping strategy for some families affected by HIV. In Uganda, denial of HIV infection in family members and avoidance of discussion of HIV in the family resulted in a lack of family support and rejection of the HIV infected family members (UNAIDS, 2001a).

The mental health of the family may have either a positive or negative effect on the HIV infected family member. Studies conducted in Tanzania (Lie & Biswalo, 1996) as well as in United States of America (Serovich, Kimberly, Mosack & Lewis, 2001) reported positive effects on the mental health of the infected people who were supported by their families. McKenry and Price (1994) added that such support increases the compliance with medical regimens. On the other hand, the infected family member may experience a range of emotions such as fear, anxiety and uncertainty for their future, depression, self-blame and self-

stigmatization as a result of the family reaction to his/her HIV status (Waugh, 2003; UNAIDS, 2001a; 2002b; Lie & Biswalo, 1996).

In view of the effects of HIV infection on the mental health of HIV affected families, which in turn have an impact on the HIV-infected family member; the researcher felt the necessity to conduct an analysis of the mental health of the family affected by the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome.

## **1.2 Problem statement**

The HIV epidemic has placed an emphasis on the role of the family in caring for those who are infected by HIV. However, the effects of HIV/AIDS on the mental health of family members as a result of multiple losses, care demands, as well as socio-economic problems related to HIV/AIDS may hinder the expected support for the infected family member. Bor and Elford (1998) argue that anything that threatens the health of the caregiver impacts on the health and well-being of those he/she cares for. It is important to highlight that not only the family's mental state hinders care, but it also causes additional emotional stress to the HIV infected family member.

Studies related to family and HIV/AIDS conducted in Rwanda only focused on the socio-economic effects of HIV/AIDS on affected families (Bollinger & Stover, 1999; USAID, 2000; UNAIDS, 2001b). Foster and Williamson (2000) state that the basic needs tend to overshadow the impact of HIV/AIDS on mental health of infected and affected people. The mental health of Rwanda families affected by HIV/AIDS has not yet been explored up-to-now. It is in this sense that the researcher felt that there was a need to conduct an analysis of the mental health of families affected by HIV in that country.

### **1.3 Purpose of the study**

The purpose of this study is to analyze the mental health of families affected by HIV/AIDS.

### **1.4 Objectives**

1.4.1 To describe the mental health of families affected by HIV/AIDS.

1.4.1.1 To identify HIV/AIDS related stressors of affected family.

1.4.1.2 To explore the emotional reactions experienced by the family members.

1.4.1.3 To explore the coping strategies adopted by the family members.

1.4.2 To describe how these reactions and strategies affect the HIV positive family member and the whole family unit.

### **1.5 Research questions**

1.5.1 What is the mental health of the HIV-affected families?

1.5.1.1 What HIV/AIDS related stressors do affected families experience?

1.5.1.2 How do they react emotionally towards those stressors?

1.5.1.3 What are their coping strategies?

1.5.2. How do these reactions and strategies affect the HIV positive member and the family as whole?

### **1.6 Significance of the study**

The findings of this will study offer to nurses and other health caregivers, infected and affected people; a better understanding of the mental health aspect of a HIV-affected family, the effects on the HIV-infected family member; particularly in Rwanda where no similar



studies have previously been conducted. The findings of this study will contribute to the body of knowledge of health providers, including nurses in terms of providing them with basic knowledge and information for planning and conducting interventions to help affected families. This will empower families to offer more effective support to their infected family member(s). In particular, the findings of this study will highlight the need for the policy makers to engage in home-based care programmes that will provide the affected families with knowledge and understanding of care-giving responsibilities by both formal and informal caregivers. As a first study conducted in the country on the mental health of family affected by HIV/AIDS, this study can be used as a pilot from which more extended research on a large scale could be conducted by nurses as well as those in other professions.

### **1.7 Operational definition**

**AIDS:** Acquired Immunodeficiency Syndrome (AIDS) is a syndrome that comes about as HIV destroys the immune system; as a result, the body loses its ability to fight infections.

**HIV:** A virus of the retrovirus family which weakens the human immune system resulting in AIDS.

**Family:** In this study, the term family includes family of origin which consists at a unit of people who have blood ties (parents, children and other relatives) as well as family of affiliation in which family member are biologically and legally unrelated, but are linked by ties of affection and commitment.

**HIV-affected family:** Families supported by Mwana Ukundwa Association that have family member(s) who is (are) HIV positive.

**Mental health:** The mental health in this study refers to the psychological state of family in terms of emotional reactions and coping strategies due to HIV/AIDS and its related care, socio-economic demands.

**Emotional reactions:** In this study, emotional reactions are the feelings and their manifestations which occur in response to stressors associated with the HIV infection.

**Coping strategies:** It is a process by which HIV affected families attempt to manage external and internal stress that occurs within the family.

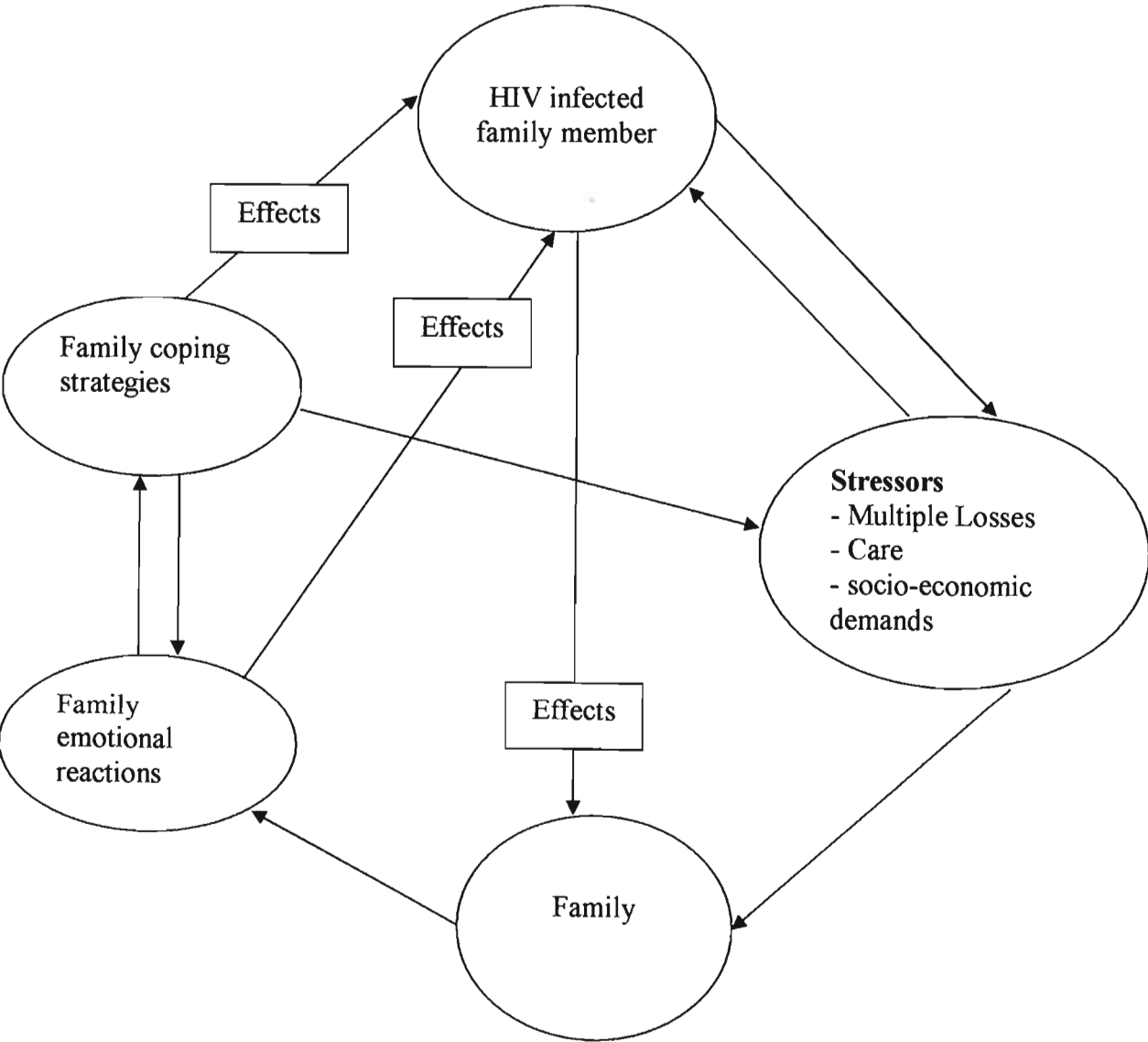
### **1.8 Theoretical framework**

Systems Theory forms the basis of the theoretical framework for this study. The Systems Theory considers the individual as a part of a large interpersonal system, which includes many parts or subsystems such as individuals (Brammerm, Abrego & Shostrom, 1993). It seeks to explain the behaviours of a complex organized system such as family in which each subsystem (family member) is connected to each other in a continuum current and ongoing process of communication and interrelationships.

Boss, Doherty, LaRossa, Schumm and Steinmetz (1993) states that the wholeness of a system is the most fundamental assumption of the system theory. System theorists argue that the whole is greater than the sum of the parts. Thus, the system can not be understood by examining isolated individual parts. It has been highlighted that there are properties and behaviours that emerge in particular systems, which cannot derive from an isolated part of the system.

In this study, the family was seen as a system in which its subsystems (family members) were in constant interaction. Hence, the diagnosis of HIV in a family member(s) affects the family as a whole. When a family member is infected by HIV/AIDS, the family experiences mainly multiple losses; such as loss of health, anticipated death and loss of future plans. The family also experiences care and socio-economic demands. These multiple losses, care and socio-

economic demands are seen as stressors for the family as well as for the infected family member. Those stressors generate emotional reactions in family members. As response, the family uses different coping strategies to deal with those emotions and the stressors as well. The family emotions and coping strategies affect-in particular -the HIV infected family member whose response affects the entire family and thus the cycle restarts. It should be emphasised that the coping strategies family members make use of, will increase or decrease family stressors.



**Figure 1 : A diagram illustrating the Systems theory on the effects of HIV/AIDS on affected families**

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter deals with review of literature on family and HIV. It is subdivided into four sections. The first section covers HIV/AIDS in Rwanda, the second consists of the effects of HIV/AIDS on family, the third looks at the mental health of the affected family and the fourth reviews the effects of emotional reactions and coping strategies of the family on the HIV-infected family member.

#### **2.2 HIV/AIDS in Rwanda**

Rwanda is located in the Great Lakes region between the Central and Eastern parts of Africa. It extends over 26,338 square kilometres (National University of Rwanda, 2004). Rwanda is a developing country. In 1998, UNIADS (2001b) reported that 70% of its inhabitants lived below the poverty line. It is estimated that approximately 38% of households are headed by women as a consequence of the war and genocide in 1994. In the study that was conducted by UNAIDS, (2001b) 83% of families that have HIV infected family members found it difficult, if not impossible, to meet the food needs as well as education, housing and clothing of families.

In 1983, the first cases of AIDS were reported in Rwanda (USAID, 2000). At the end of 2001, according to UNAIDS 11.1% of adult population were living with HIV/AIDS (UNIADS, 2002a). Actually, the numbers of those living with HIV/AIDS are estimated at 13% (Commission Nationale de Lutte contre le SIDA au Rwanda, 2004). Rwanda is listed amongst nine African countries most affected by the HIV/AIDS epidemic (USAID, 2004). According

to Commission Nationale de Lutter Contre le SIDA (2004), the HIV prevalence is higher in the age group of 25-45 years that is those who are still in their most productive and procreative lives. Small scale studies conducted in Rwanda reported that 27% of pregnant women were infected in some urban cities, but far lower rates (just 1%) were found in rural areas, where most people lived. The high population movement from one district or province to another and migration changed that pattern. By the year 2000 the gap was closing (USAID, 2004). HIV/AIDS is one of three leading causes of death amongst Rwanda population. As a result, the numbers of orphans has increased. In 2001, it was estimated the 264, 000 of children were orphaned by AIDS (UNAIDS, 2002a).

The factors contributing to the spread of HIV/AIDS in Rwanda include economic hardship, war and genocide which led to the rape of women and children; movement of population; high rates of multiple sex partners; widespread availability of commercial sex; low use of condoms, and resistance to open discussion about the disease. In addition, low literacy poses barriers to the implementation of HIV/AIDS education campaigns (USAID, 2004).

### **2.3 The effects of HIV/AIDS on family**

HIV/AIDS infection has emphasised the role of families in caring for those living with this disease. Early in the epidemic, the lifespan of an AIDS victim was short. Today, with the improvement of care of those infected such as the use antiretroviral drugs and other effective treatment of opportunist diseases; the possibility exists to extend the life span of HIV-infected persons. This extended trajectory means that there are now more people living with HIV/AIDS than ever before, and the potential needs for informal care-giving is also extended (Wight, Aneshensel & LeBlanc, 2003). Lesar and Maldonado (1997) assert that caring for HIV infected-persons presents extraordinary physical and psychological care, as well as

socio-economic demands. Such demands have potential to strain the well-being of family in all aspects, including the mental health of the family

### **2.3.1 Multiple losses**

HIV/AIDS infected and affected people experience multiple losses associated with HIV/AIDS. The latter is still an incurable disease despite the discovery of antiretroviral drugs that delay the course of infection. During the AIDS phase, the body loses its immunity and thus increases the potential of acquiring different opportunistic infections (Jackson, 2002). Related to this, the loss of health is common among HIV infected people. Steinberg et al. (2002) mention that during the AIDS phase, the infected person loses a number of body functions and even the ability to care for himself/herself.

Since the diagnosis of HIV infection, both infected and affected family members start to anticipate the death. It is reported that the infected person experiences his/her anticipated loss of life as well as losses of those he/she will leave behind when he/she dies (Ingram & Hutchinson, 1999). Studies conducted by Mallinson (1997) and Siegel and Gorey (1998) revealed that the affected people may experience repeated deaths due to the fact that HIV/AIDS is a transmittable disease.

Infected and affected people experience losses of their social connection. This is on one hand due to the lack of time for social activities as one is either sick or caring for the sick family member (Alma & Ilene, 1997; Melnyk et al., 2001). On the other hand social loss may be linked to stigma and discrimination related to HIV/AIDS. This is the case when infected and affected people isolate themselves and/or the community stigmatises and discriminates them (UNAIDS, 2001a; International Center for Research on Women [ICRW], 2002). Mallinson (1997) reported that affected people lose their social connection as a result of death of their



dear friends. Losing one's social connection affects the natural course of life. This is true in families where members prematurely become orphans or widows.

Economic loss is also common in families affected by HIV/AIDS. This is not only related to the care-cost but also to the loss of employment on the part of infected and affected people and hence a decrease of family income (Cody, 2000; Steinberg et al., 2002). Foster and Williamson (2000) reported that in sub-Saharan Africa HIV affected children drop out from school due to financial problems and HIV/AIDS-related care responsibilities.

### **2.3.2 Care demands**

Care demands begin as soon as the HIV infection is diagnosed and perhaps even before; when it is just suspected in family member(s). This could be during the asymptomatic or symptomatic phase, as some people take HIV testing when they start to develop symptoms or illnesses related to HIV. In a study conducted in Rwanda, 80% of participants reported that they were motivated to take HIV test by the presence of symptoms or illnesses that caused them to suspect that they may have HIV (UNAIDS, 2001b). Emotional care may be one of the first care needs, as the diagnosis of a life-threatening disease such as HIV/AIDS results in emotional reactions. This is due to the anticipatory loss of health and eventual death. It affects both the infected family member and the rest of the family (Van Dyk, 2001). McKenry and Price (1994) emphasize that usually families are a major resource of emotional and social support in chronic illness. Family members are people who share frustrations, discouragements, and despair of living with the infection.

As the HIV progresses to AIDS, the level of required care required increases. The infected person develops symptoms and illnesses related to HIV. He/she loses control over bodily functions, while his/her ability to take care for himself/herself has also been lost (Steinberg et

al., 2002). In such a situation, family support is very crucial to the HIV infected family member (Jackson, 2002). The family care involves care-giving activities such as feeding, bathing, medicating, accompanying the ill to health services, as well as looking after him/her (McKenry & Price, 1994; Foster & Williamson, 2000). It has been reported that care-giving demands fall mostly on women in the family (Jackson, 2002; Steinberg et al., 2002; Desmond, Michael & Gow, 2000). Desmond et al. (2000) mentioned that women are often given the added burden of having to care for the ill in addition to the family duties they typically perform; while possibly also being infected. Alternatively, children, particularly girls; are taken out of school to care for the sick or to help with the family duties, other relatives may move in with the family in order to assist them (Steinberg et al., 2002).

People with HIV/AIDS have potential of exhausting their social support resources (Wight et al., 2003). A study conducted in Sub-Saharan Africa showed that caring for people infected with HIV/AIDS is burdensome to the caregivers. This is reinforced by the knowledge that there is no cure. Despite the good care the infected person receives, he/she will die soon (ICRW, 2002). Boyd-Franklin, Steiner and Boland (1995) argued that though family members are known as towers of strength in regard of care-giving, it does not exclude the fact that HIV/AIDS-related care demands become too great for them. The care-givers may find themselves under intolerable demands, and may burnout as their role is extended (Jackson, 2002). McKenry and Price, (1994) asserted that the physical and emotional burdens of this care-giving are enormous and can result in serious adverse effects on the physical and mental health of the caregiver. In addition, family members face the emotional stress related to witnessing their loved one suffering and coming to the end of his/her life.



### **2.3.3 Social demands**

There will be important social effects on a family with or HIV infected family member. It may result in social disruption within and outside the family (Lesar & Maldonado, 1997). McKenry and Price (1994) mention that families are products of both sub-systems (individual members) and para-systems (community, culture, Nation). A family does not live in isolation; it is part of large social context. The effects of HIV/AIDS on the social aspects of the family include family dynamics and its interaction with significant others.

#### **2.3.3.1 Family dynamics**

The demands of caring for the infected family member affect family relationships and family life. Health care regimens are time consuming, rigorous and burdensome. The time has to be divided between normal responsibility and care demands. This may be taxing to the family members. The infected family member tends to attract all attention of the family while the rest of family members seem to be forgotten. HIV induces change in the family lifestyle. Normal routines are interrupted, and shared activities are forgotten. The family role and responsibilities change (McKenry & Price, 1994; Melnyk et al., 2001).

Foster and Williamson (2000) highlight that the children may experience a poor quality of life as their parents have to take care for the infected family member. Gow and Desmond (2000) mentioned that the caring by someone who is exhausted by illness or care demands may have negative impact to the well-being of the children. Some families split up even before the death of parents, and children are placed in foster care. Others children may be forced into a parental role. With this, emotional needs of children are still overlooked (Virginia & Janice, 1994; Steinberg et al., 2002). The family should balance between the needs of the infected family member and those of the rest of the family.

Emotional reaction and stigma lead to the disruption in family interaction; mainly in terms of communication (Beverley et al., 2001; Waugh, 2003). HIV infection induces secrecy around the infection, and family members are forced to deal with HIV-related emotions without any support either from the family or others. Schoka, Bert, Patricia and Christina (2003) argued that communication is one of the major components of family system function and growth. Thus the quantity and quality of verbal and non-verbal communication within the family system is crucial to the healthy relationship amongst family members. However dysfunctional family communication seems to be common in families affected by HIV/AIDS. In the study conducted in Uganda, HIV positive participants did not choose their partners as their significant other to whom they could disclose their status (UNIADS, 2001a).

Siegel and Gorey (1998) mentioned that children are not told the true diagnosis of the HIV-infected family member. They may witness their family members- or even themselves- dying without knowing the cause of the disease (Siegel & Gorey, 1998; Haven & Mellins, 2004). It has been argued that such a decision is based on a desire to protect children from perceived hardships, overwhelming emotional reactions and stigma that they may experience once their status is disclosed to others outside the family. Beverley et al. (2001) argues that it is not surprising that in the face of such a powerful stigma, families choose to keep their HIV status a secret. In this case, the secrecy is motivated by the shame and fear of social consequences. Perhaps the lack of open discussion on the infection may be associated with parents or other family members' own concerns about facing questions about death, or how one became infected, as well as their unresolved HIV-related emotions (Campbell, 2003). In his study Owens (2003), found out that HIV affected families deny the infection and avoid talking

about it. Self-blame was also mentioned as a barrier to communication.

The lack of open communication about HIV/AIDS may be considered as one of the major threats of family dynamics. It is also an indication of psychosocial problem in that family (Schoka et al., 2003). Although the need of discretion in disclosure is clear, an unfortunate consequence of such a secrecy, the families will not receive the much need support that can ease the suffering from the stressful event.

#### **2.3.3.2 Interaction with significant other**

Beside the disruption in social interaction within family, HIV/AIDS leads to the change in normal interaction between the family and significant others. Such disruption can be attached to the care demands that prevent the family from engaging in normal social activity as well as the decrease in the economic status of the family (Melnik et al., 2001). Furthermore, the families social disruption is thought to be related to the stigma around the infection. Stigma and discrimination is not uncommon amongst HIV affected families. UNAIDS (2001a), assumes that HIV-related stigma and discrimination are universal, occurring in every country and region of the world.

UNAIDS (2002b) describes the stigma as a process of devaluation of an individual as certain of his/her attributes are seized upon and defined by others as discreditable or unworthy. Stigma results in discrimination as stigma-related negative thoughts often lead people to do or omit to do things, in regard of the stigmatized individual. Thus, the individual is treated unfairly and unjustly, on the basis of their belonging or being perceived to belong to a particular group (UNAIDS, 2001a; UNAIDS 2002b). Families affected by HIV/AIDS may isolate themselves due to the fear of rejection. If friends learn that there is an infected person

within a family, they may grow distant and refuse to allow their children to play with the children from affected family (UNAIDS, 2001a; Seligson, 2004).

The stigma is mostly associated with the moral judgment attached to the HIV as the latter is sexually transmitted (Jackson, 2002) and a lack of accurate and detailed information on HIV/AIDS. The findings of the study conducted in Ethiopia, Tanzania, Zambia (ICRW, 2002) and Uganda (UNAIDS, 2001a) revealed the fear attached to the HIV epidemic may interact in unexpected way with that knowledge. This leads to stigma and discrimination. However, it was also reported that people hold both accurate and inaccurate information while others lack detailed information on the infection.

In summation, HIV/AIDS results in social disruption within and outside the family. This may be experienced as stressor for affected families.

#### **2.3.4 Economic demands**

The impact of HIV/AIDS on families has been repeatedly reported (Foster & Williamson, 2000; UNAIDS, 2001b; Desmond et al., 2000; Steinberg et al., 2002). HIV is a long-term medical condition that involves medical costs. In addition to financial demands of payment for HIV-related illness treatment, some family members are diverted from income generating activities. The family finances worsen when parents have to relinquish income-generating activities in order to stay at home and care for his/her own sickness and the sick child. If the male, he leaves an economic gap in productive which women and children have to fill. Clearly, the family income falls while costs increase. It is thought that the declining productivity related to HIV/AIDS is primarily and initially felt within the family (Desmond et al., 2000).

HIV/AIDS adds a financial burden to an already complicated life. Foster and Williamson (2000), found out in Sub-Saharan Africa, the impact of HIV/AIDS on families is compounded by the fact that many families live in communities that are already disadvantaged. Findings from National Health Accounts revealed that in Rwanda, 83% of families that have HIV infected family members found it difficult, if not impossible, to their meet the basic needs- such as housing and education (UNAIDS, 2001b). In the same study, it was reported that health expenditure was paid through out-of-pocket payment by sero-positive patients and their families as the majority of Rwandan do not have health insurance. It is important to highlight that only 26% families that participated in the study were able to meet the costs of health services exclusively from their own resources. The rest rely on financial assistant from churches and other NGOs, borrowing, or the sale of assets (UNAIDS, 2001b). In their study Koopman, Felton, Marouf, Butler, Field, Gill, Chen, Israelski and Spiegel (2000) found that a low income is perceived as a stressor by HIV infected and affected people.

## **2.4 Mental health of affected family**

A National Health Plan for South Africa (1994) associates the mental health of an individual to his/her social, physical and spiritual well-being as well as material conditions. The mental state of an individual affect and is affected by these components.

HIV and AIDS are seen as a direct threat to the mental health of individuals infected and affected, as it implies inevitable death of a loved one (Van Dyk, 2001). The infection also affects the mental health indirectly through the care and socio-economic demands experienced by the affected families (Lesar & Maldonado, 1997). It is necessary to mention that physical and socio-economic aspects of the family are known as protectors of its mental health (Kreigh

& Perko 1983; McKenry & Price, 1994). However, HIV/AIDS affects these protectors and turns them into family stressors.

#### **2.4.1 Family emotional reaction to HIV/AIDS**

According to Thompson and Mathias (2002), emotions involve conscious perceived feelings and their manifestation which occur in response to a stressor that triggers its arousal. In the case of HIV/AIDS, the anticipatory death of the HIV infected family member and other multiple losses, care, and socio-economic demands may be considered as triggers of emotions experienced by members of the affected family. It should be highlighted that children are as emotionally affected as the adults. Dowdy, Kiev, Lathrop, Lantz, and Winkle (1997 as cited in Beverley et al., 2001) referred to children as the forgotten grievers. A study conducted amongst HIV affected children in Sub-Sahara Africa reported that the mental health of these children seems to be overshadowed by socio-economic impact of HIV/AIDS (Foster & Williamson, 2000).

One of the most feared stressors within a family is a diagnosis of a life-threatening condition at a family member such as HIV/AIDS (McKenry & Price, 1994). Melnyk et al. (2001) argues that a full comprehensive of the diagnosis does occur simultaneously with initial diagnosis. On being told that one of the family members is infected, the family members may initially be shocked. It is even more shocking when one was not suspected to have the virus. Usually, shock induces a period of denial or disbelief, which may be seen as coping strategy employed to help people adapt to the threatening news (Chippindale & French, 2001; The International Biological Serum Clinics, 2003; The American Psychiatric Association, 2003). Parents of a newly diagnosed child reported being shocked with the diagnosis as they had not been tested themselves (Barrett & Barrett, 1994). However, with time the news sink in and family

members realise the meaning of the HIV/AIDS diagnosis. This is followed by variety of emotional reactions that are in line with those associated to the anticipated death of the infected family members (Van Dyk, 2001).

Anger is not uncommon in families affected by HIV/AIDS. The family may feel anger at towards the infected family member for having a self-destructive life style and other related burdens he/she may have brought to the family (Bor & Elford, 1998; Lie & Biswalo, 1996; ICRW, 2002). The family members may also experience self-blame, guilt, and shame. Beverley et al. (2001), report self-blame amongst parents of HIV infected children. Children are also known to have experienced self-blame in regard to their parents infection. If the children do not have accurate information; they may see the parents' condition as a punishment of their misbehaviour (Bor & Elford, 1998).

Fear and anxiety in affected families are mostly associated to the anticipated death of the infected person. This may result in the feeling of uncertainty of the future of the family unit (Melnik et al., 2001). In a Ugandan study, most of the children expressed fear related to the loss of a parent due to AIDS (Foster & Williamson, 2000). Bor and Elford (1998) mention that children may be worried about their own future health, as they may fear that they will also become infected through casual contact. However, the HIV/AIDS fear amongst children is often overlooked. The fear of acquiring infection is also common amongst caregivers (Seligson, 2004). The fear and anxiety is also associated to the decrease in the family economic situation. This leads to uncertainty about the future of the family (Barrett & Barrett, 1994). HIV affected families also fear the social consequences of HIV infection such as stigma and discrimination (UNAIDS, 2001a; Beverley, 2001; ICRW, 2002).

Depression and sadness are also associated with HIV/AIDS. An HIV-affected family may experience social withdrawal; a sense of abandonment; feeling of unworthiness; profound sadness and a lowered sense of self-esteem. Feelings of helplessness and hopelessness are also experienced. There may also be a lack of interest in work and other activities as well as suicidal thoughts and chronic sorrow (Foster & Williamson, 2000; Melnyk et al., 2001; Beverley et al., 2001). Depression is associated with the anticipated eventual loss of the loved one. It is also related to the consequences of the infection to both the individual and family. These include unemployment, stigma and discrimination, socio-economic loss and lifestyle changes. In addition, the infected person continues to deteriorate despite the care provided to him/her.

HIV affected family members may experience a mixture of emotions towards the infected family member. Beverley et al. (2001), report that HIV affected parents related that on one hand they felt sad to know that their child was HIV positive, yet on the other hand they experience a sense of joy due to the fact that, despite the infection, the child's health was stable. In a study conducted amongst members of affected families, it was revealed that while they may experience the anger against the infected person and feel burdened by him/her, they do feel sorry for what he/she is going through and are willing to support him/her. The family may love the infected person and feel obligated to care for him/her (Siegel & Gorey, 1998).

These emotional reactions to the diagnosis of HIV in family are normal. However in some cases they become complicated and need special intervention (van Dyk, 2001). HIV may also act as a trigger to psychiatric disorders for those who are at risk of developing obsessive-compulsive, depression, phobic anxiety, and paranoia.



#### **2.4.2 Coping strategies**

Coping is a process by which an individual attempts to manage external and internal stresses that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984 in Melnyk et al., 2001; Uys & Middleton, 2004). Coping strategies involve a large array of covert and overt behaviours. Uys & Middleton (2004) state that defence mechanisms may be considered as unconscious coping strategies. They add that individual tends to repeat the coping strategies that are seen as successful, thus those coping strategies become part of individual's repertoire. Mckenry and Price (1994) point out that coping is a process of establishing balance in the family system. Thus, in the presence of any threat to family such as HIV/AIDS infection, the family members may employ a range coping strategies.

In a presence of a stressor, the family members appraise it cognitively and conclude if the event is threatening for them or not. The way the family appraises that stressor determines the impact that particular event has on the family; as well as the reactions and coping strategies that follow (Uys & Middleton, 2004; McKenry & Price, 1994). Coping strategies may be used for two parallel functions, namely to regulate the emotional response (emotional-focused) or to cope with the threat event itself (problem-focused) (Lazarus & Folkman, 1984 in Melnyk et al., 2001).

A number of coping strategies have been used by families affected by HIV/AIDS. Some of them are seen as effective and supportive for both infected and affected family members. In their study, Beverley et al. (2001) reported that HIV affected family members become closer emotionally and support each other if they openly discuss the infection. The family members strive to normalise their situation by maintaining the sense of family well-being and hope despite the infection. McKenry and Price (1994) mentioned that emotional closeness and

cohesiveness of family are crucial for dealing with a chronic illness. In her study on spiritual care, Mahlangu (2001) reported that faith helps people to accept their condition and experience peace of mind- as they develop a meaningful relationship with God.

Beside the emotional-focused coping strategies, those families work together to cope with the demands related to the HIV infection. Foster and Williamson (2000) and Beverley et al. (2001) report that the family members reorganise themselves to take care for the HIV infected family member. They organise family priorities and prepare for the future. This may require the family members to renegotiate their role and responsibility, as well as to look for the support from outside the family (McKenry & Price, 1994; Beverley et al., 2001; Foster & Williamson, 2000).

Coping strategies may also be unsupportive and reinforce the stressor. Some defence mechanisms such as denial; can be employed to cope with the infection and related demands. Denial is common immediately after learning about HIV family member status (Melnik et al., 2001). Such denial is known to help people to get used to the threatening news (Chippindale & French, 2001; the International Biological Serum Clinics, 2003; American Psychiatric Association, 2003). However, it has a negative effect when it lasts and prevents the family members from provide the needed care to the infected family member. In his study amongst American African women living with HIV/AIDS, Owens (2003) reported that the affected families deny the infection and its related demands. They avoid talking about it. The same findings have been reported in Uganda; when in addition to the denial, HIV infected family members experience rejection from their families (UNAIDS, 2001a).

In the presence of chronic illness and its related demands some families may collapse under the emotional strain and disintegrate through divorce or separation (McKenry & Price, 1994;

UNAIDS, 2001a). To cope with the stigma around the HIV infection, Ugandan families affected by HIV/AIDS avoid social contact UNAIDS (2001a). Tomaszek, (2001) suggests that such behaviour may be used to protect themselves from possible maltreatment. However, it cuts off available support. This implies that family members are forced to deal with multiple psychological and emotional ramifications of being infected or affected with little or no support. Tomaszek (2001) highlights that in such a situation, affected family members are at risk of a mental health disorder, (depression, PTSD, and anxiety), behavioural problems (drug and alcohol, inability to maintain employment, school failure, and criminal behaviour).

## **2.5 The effects of emotional reactions and coping strategies of the family on the HIV-infected family member.**

The Systems Theory suggests that family is a system in which its subsystems (family members) are in consistent interaction. In this position, the mental state of one of the family members influences the whole system (Brammer, Abrego and Shostrom, 1993). Thus the HIV-related emotions and coping strategies of the family members may be experienced as supportive or not on the part of the infected family member. This may not only affect his/her mental health, but also his/her physical health as well as socio-economic aspects of his/her life (Serovich et al. 2001).

In a Tanzanian study, HIV infected patients reported that when their families accepted and cared for them, they experienced an utmost sense of belonging (Lie & Biswalo, 1996). It is worth noting that HIV/AIDS leads to self-stigma, by internalising thoughts and reactions of others (UNAIDS, 2002b). In this case, the HIV infected individual may feel unworthy and fail to accept himself/herself and his/her condition. When an HIV-infected individual experiences acceptance from his/her family, he/she in turn accepts himself/herself and his/her situation (Egan, 1994). In the study conducted by Owens (2003), participants reported that care, love and empathy from their family reduce depression that is associated with being infected. In

addition to that, being with their family members and getting involved in the family activities were seen as a distraction from thinking about their HIV status.

Concrete support, such as caring for the infected family member and providing for financial needs reduce the fear and anxiety on the part of infected family member. Serovich et al. (2001) found out that people living with HIV/AIDS experience less depression, loneliness and anxiety as a result of the family support. They highlight that the perceived support rather than actual support, was correlated with mental health on the part of infected family member. Participants asserted that just believing that family support would be available, is comforting. In such a situation, the infected family member is encouraged to take care of himself/herself and fight against the illness. McKenry and Price (1994) mention a correlation between family support and treatment compliance amongst people who are chronically ill.

On the one hand the family reactions to the HIV infected family member may be seen as source of additional emotions to that generated by HIV infection itself. A range of emotions such as fear and anxiety, uncertainty for the future, depression, self-blame and self-stigmatization on the part of infected family member were reported as result to the family reaction on his/her HIV status (Lie & Biswalo, 1996; UNAIDS, 2001a; UNAIDS, 2002b; Waugh, 2003). Related to that, it may be difficult for the infected family member to follow the needed treatment regimen, and thus the course of infection become shorter. It should be noted that there are assumptions that psychological problems influence the course of HIV infection (Rice, 2002). La Via and Workman (1998 in Rice, 2000), state that thoughts, emotions and behaviours activate anatomical and biological pathways, which in turn modulate immune function.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 Introduction**

This chapter presents the study's procedures for obtaining and analysing the data. It includes the research design, site of study, population, sample and sampling method, research instrument, validity and reliability, data collection, analysis and the ethical consideration.

#### **3.2 Research design**

This was a qualitative study, which involved the examination of the phenomena in a holistic manner through the collection of rich and detailed narrative data (Polit & Hunger, 1999).

Researchers who use qualitative approach assume that there are multiple interpretations of reality and the goal of research is to understand how individuals construct reality within their contexts. The philosophy behind qualitative study is that the reality is not a fixed entity but rather is constructed by individuals and many constructions are possible (Holloway & Wheeler, 1996; Polit & Hunger, 1999).

Brink (2002) states that a qualitative approach is useful for the exploration of meaning and description, as well as promotion of understanding of human experiences from the point of view of the research participants, and in their context in which the action takes place. This requires the researcher to interact with the research participants (Polit & Hunger, 1999).

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To achieve the purpose of this study and answer the research questions, it required collecting detailed information about participants' lived experiences as members of a family affected by HIV/AIDS. It is necessary to highlight that the phenomenon of interest in this study had not been explored in Rwanda. Hence it was thought that a qualitative approach would generate clear insight on that phenomenon (Polit & Hunger, 1999).

A case study design was used to describe the mental health of the HIV-affected families and its effect on the HIV infected family member(s). According to Polit and Hungler (1999) a case study is an in-depth investigation of single entity or small series of entities. It involved extensive study. While the number of the subjects was small, the number of variables related to the situation were deeply explored (Carmack, 1991). Yin (2003) adds that a case study allows the researcher to retain holistic and meaningful characteristics of real life event.

Robson (1993) argues that case study provides the researcher with the opportunity of gathering significant amounts of information from participants' perspectives not only to their present experiences, but also to the past ones and gives a contextual and holistic picture of the unit(s).

The case study design can be used in both qualitative and quantitative studies and it is known for its flexibility (Robson, 1993; Yin, 2003). Its methodology can be pre-structured or emergent or fall in middle of these two extremes. The case study design permitted the researcher to use a number of methods so that case may be illuminated from all sides (Carmack, 1991). A case study helps to answer the types of questions such as what, who and why questions (Polit & Hunger, 1999; Yin, 2003). Therefore, it could be used to explore and describe the phenomenon of interest.

The case study was the most suitable methodology for this study as it allowed the researcher to use the family as a unit to be studied holistically and contextually.

Lincoln and Guba (1985) add that case study is useful when there is little prior research on the phenomenon and provides the preliminary data for planning large research studies as it was the case in Rwanda.

### **3.2.1 Definition of the case study**

Holloway and Wheeler (1996) define a case study as “entity which is studied as a single unit and has clear boundaries” p.156. The case study was the family who had a family member infected by HIV/AIDS. It should be highlighted the study included the units (family) in which the HIV member had disclosed his/her status. The family members who participated in the study were aware of his/her status. The infected family member was also included in the study sample.

### **3.3 Site of study**

This study was conducted in Mwana Ukundwa Association in Kigali, Rwanda. Mwana Ukundwa Association is a local non-governmental organisation that takes care of orphans. To assist those orphans, the Association collaborates with their foster families.



As some of those orphans and/or their foster family members are HIV positive, the Association runs a project to support the affected families. Mwana Ukundwa Association supports thirty HIV/AIDS affected families in Kigali. The assistance consists of medical aid and providing food. HIV-infected family members form a support group in which members receive social and spiritual support.

The reason for choosing this site was because this association was the one that supported HIV/AIDS infected people together with their families. However, little attention was given to the family members' mental health. Though, the experience of affected families supported by Mwana Ukundwa Association cannot be generalised, the findings of the study gave an insight on the phenomenon under study. This can be useful to other similar organisations. In view of the time and the means that the researcher had, Mwana Ukundwa Association was the most accessible site for the study.

### **3.4 Population**

This study targeted families affected by HIV/AIDS who were supported by Mwana Ukundwa Association. The HIV-infected family members of families supported by Mwana Ukundwa Association were in different categories (children, parents, relatives and non-relative). This gave the researcher opportunity of gathering more diverse experiences according to who was infected in the family unit.

### **3.5 Sample and sampling method**

Yin (2003) suggests that the multiple case study is better than single case study. He argues that at least two case studies give a chance of collecting data with multiple experiences and



perhaps different experiences. This provided the researcher with more compelling and robust information. Related to this, a multiple case study was used in this study. The expectation of finding at least four families was not achieved as the researcher found only two families. This was due to diversity of the families that are supported by the Mwana Ukundwa Association and the time limits for data collection. Two infected people who participated in the study represented different age groups (young people and adults) of people supported by the Association, and the position of the infected person in his family. The sample included all family members who were aware of the HIV status of the infected family member including the infected family member himself/herself.

Qualitative studies mostly use non-probability sampling. In this study, a purposive sampling was used. Holloway and Wheeler (1996) state that purposive sampling involves selecting participants and settings according to criteria set in respect of what data the researcher wants to collect. The researcher identified certain criterion to be applied in sampling and the sample is chosen accordingly.

Purposive sampling is used to get participants that are judged to hold specific knowledge about the phenomenon. People who have undergone or are undergoing an experience, about which the researcher wants to gain information, are most suitable. The purposive sampling results in samples that share some characteristics (Holloway & Wheeler, 1996). In this study, the researcher sampled the families that have one or more members who were infected with HIV. The researcher selected HIV-infected people who had disclosed their status to their families. After encouraging them to participate in the study, the researcher met their family members as well- to obtain their informed consent to participating in the study. The families were also selected according to which members in the family was infected. As result, the

sample included families in which a parent was infected and families in which a child was infected. This was thought to bring broader and diverse information on the phenomenon of interest.

### **3.6 Data collection**

Data was collected by using individual face-to-face interviews and focus group semi-structured interviews. The use of a semi-structured interview elicited rich information about the phenomenon of interest. The interview helped to consider participant priorities, validity, high response rate and therapeutic (Denscombe, 1998). An interview is useful and is recommended for collecting data on sensitive issues such as emotions, experiences and feelings. Such studies need to be handled carefully and may require the researcher to coax the participants to be more open (Denscombe, 1998; Polit & Hunger, 1999). Semi-structured interviews required the use of a research schedule, which was a guideline for the interviewer and contains questions and themes that were important to the research (De Vos, 2002). However the researcher was flexible in terms of order and she allowed interviewees to develop ideas and speak more widely on the raised issues (Denscombe, 1998).

The interview was the suitable method for data collection in this study as it was looking at the experiences and emotions of HIV affected families. The phenomenon under study was known to be a sensitive topic which some people are reluctant to discuss. The interview schedule helped the researcher to cover all the questions related to the study, and yet allowed the participants to elaborate on the topics and start with any question as they felt appropriate. The researcher started by building a relationship of trust with the participants. Communication skills such as active listening, probing, rephrasing, and summarizing were used to ensure that the researcher understood participants and help them to share their experiences.

Focus groups allowed the participants to share new ideas and consider a range of views before answering the questions. The researcher facilitated the discussion using an interview schedule and ensured that all the topics were covered. In this study, the focus group was called to complete the information gathered during individual interviews. It was hoped that new information would emerge as the family as a group were discussing on the same questions used in individual interviews together.

Visit	Activity
1	The interviews took place at participants' home. First visit consisted of introducing the study, getting informed consent and establishing rapport with family members.
2	Collecting data from individual family members- the aim of which was address the research objectives and questions.  Obtaining consent from members who were not present at previous visit.
3	Participants from the same family met together in their family focus groups.  The same interview-guide as the one used for individual interviews was used to encourage participants to discuss and share their experiences together regarding the phenomenon.
4	Validate data collected and redress areas that had been previously missed.

**Table 1: Data collection schedule**

Interviews took place at the participants' homes. However, the participants had a choice to meet the researcher at Mwana Ukundwa Association Office if they felt the privacy could not be maintained at their homes. The interviews were conducted in Rwandan and recorded on audio-tapes. Afterwards, the interviews were transcribed and translated into English by the researcher and other two expert translators of Rwandan. To ensure the accuracy of the translation, each translator and researcher did independent translations, and afterwards the translations were compared.

### **3.7 Research instrument**

An interview schedule (see Appendix E) was used during both the individual and focus group interviews. The interview schedule was developed according to the objectives and research questions of the study. It contained open-ended questions that helped the participants to talk freely about the topic. Open-ended questions were those questions that require more than "yes" or "no" answers. This gave the participants opportunity to elaborate more on the topic according to their viewpoints. The researcher also developed a case protocol that guided data collection and analysis procedure (Appendix F).

The interview instrument was translated in Rwandan, which is the mother language for both the researcher and study participants. After translating the interview instrument by the researcher, it was given to the Rwandan translator for verification and another translator retranslated it again in English, as method to ensure the accuracy of the translation.

### **3.8 Data analysis**

Qualitative data analysis involves analyzing amounts of narrative data instead of numbers as in quantitative study (Brink, 2002). To analyze the data of this study, an editing analysis was used. According to Polit and Hunger (1999), in editing analysis, the researcher acts as the

interpreter. The researcher searched for meaningful segments and units of data. Once these segments were identified and reviewed, the researcher developed categories and themes. Yin (2003), suggests that in case studies, the categories should be in line with the research objectives and conceptual framework. Hence, the themes and categories of this study were developed according to the research question and conceptual framework. Those categories were discussed with other researchers who are knowledgeable in the field.

No new information emerged during focus groups. Data collected in the focus group confirmed what was said in the individual interviews. Therefore, data from individual and focus group interviews were analysed together. Besides confirming data from individual interviews, the focus group helped the participants share between them what they had not been able to talk about before. In this case, the focus group was seen as family therapy. The two cases were analysed separately. In addition to that, a cross-case analysis was done to explore the similarities and differences between the two cases. The findings of the study was compared with previous related studies and related theories.

### **3.9 Trustworthiness**

The qualitative studies use credibility, transferability, dependability and conformability to develop effective evaluation of the quality of data collected (Holloway & Wheeler, 1996). Credibility consists of ensuring that the subject of inquiry is well identified and accurately described (Robson, 1993). The researcher strived to accurately understand and present the realities of the participants as they were constructed by them in respect of the phenomenon under study (Guba & Lincoln, 1989). To ensure the credibility of this study, the Member-Checks were used. Guba and Lincoln (1989) argue that Member-Checks are the best techniques to enhance the credibility of data collected. It allows for verifying data with those



who provided them. After transcribing data, the researcher met the participants to verify if what was written was what they had intended to communicate, as well as the accuracy of the preliminary analysis.

Due to the sample size and the sampling method used in this study, data and findings of this study, like other qualitative studies could not be generalized. However, they can be transferred to other populations. To ensure the transferability, the researcher provided the full account of the theoretical framework used in this study, and careful description of the time, place and context in which the data was collected. Hollow and Wheeler (1996) add that such detailed information helps readers decide whether he/she can transfer the findings of the study to other situations or settings.

Robson (1993) argues that a credible study can also be dependable. The dependability consists at ensuring the stability the data over the time (Guba & Lincoln, 1989). Robson (1993) adds that “when the process followed is clear, systematic and well documented and provide a safe guide against bias, this is dependability test” p.407. To ensure the dependability of data of this study, other researchers audited the process of gathering data and the interview schedule in order to evaluate their quality and appropriateness. In addition the protocol was be used.

Conformability involves assuring that data can be tracked back to its original source and that the findings flow from that data and not just from the researcher’s imagination (Robson, 1993; Guba & Lincoln, 1989). To confirm data and findings of this study, the conformability audit was used. The interview transcripts, data analysis process and the findings were audited by the research supervisor to confirm the data flow from their source, and if the process by which the final findings were obtained can be confirmed.

### **3.10 Ethical consideration**

The research proposal was presented to the School of Nursing, University of KwaZulu-Natal, where research committee approval to conduct the study was obtained (Appendix A). An application letter from the researcher was submitted to the Coordination Office of Mvana Ukundwa Association (Appendix B). This was submitted together with a copy of the research proposal and the research committee approval form. Once the permission was given from the above authority (Appendix C), the researcher identified the families that could provide the information needed for the study. The researcher met each family to explain the study and its purpose, as well as the methods for data collection. The participants were informed about the use of a tape-recorder during interviews and were assured that information obtained would be used for research purpose only. Pseudonyms were used in research report to maintain anonymity. Participants were also informed of their rights to withdraw at any stage of the study, if they felt uncomfortable. This information helped the participants to sign a written form of consent once they were willing to participate in the study (Appendix D).

Regarding confidentiality, pseudonyms were used in interviews and research reports.

Pseudonyms were also used for the name of the areas in order to maintain confidentiality.

Interviews were conducted in a private room at the participants' homes according to the choice of each participant.

## **CHAPTER FOUR**

### **DESCRIPTION OF FINDINGS**

#### **4.1 Introduction**

The present chapter is divided in two sections, namely sample realisation and description of case studies and findings of the study.

#### **4.1 Sample realization and description of case studies**

##### **4.1.1 Sample realization**

The population of the study was families affected by HIV/AIDS that are supported by the Mwana Ukundwa Association. The researcher started by identifying different categories that were represented in those families according the age group of the infected family member and his/her position in the family. As result three age categories were identified that are children, young people, and adults. Two categories were identified in respect of the position of the infected family members namely child or parent.

HIV infected children were not aware of their HIV status. It is only their parents who knew their status. In some families, particularly where the infected family member was an adopted child, only the mothers would be aware of the child's HIV status. They would not reveal the status to siblings and husbands due to the fear of stigma and discrimination and possible rejection of the child. As a result of this, it was not possible to include HIV infected children in the study. The researcher could not risk unwanted disclosure of the child's status, nor get enough participants in families where even the infected family member was not aware of his/her HIV status.



Regarding the position of the infected person in his family, HIV infected participants were either children or parents. It should be noted that some of these children were adopted. Two families who represent these four categories were chosen. In one case, the infected family member was a young person and in the position of a child within her family. In the second case, the infected family member was an adult and in position of parent within her family. It should be noted that by that time of data collection, most of HIV infected people supported by the Association were females. Thus, HIV infected people who participated in the study were only females.

#### **4.1.2. Description of the case studies**

##### **4.1.2.1 Case I**

It should be noted that as mentioned in the ethical consideration section, pseudonyms were used to ensure both participants and their areas for confidentiality.

The family was located in Biryogo area, Nyamirambo district, Kigali city province. This is one of Kigali city's areas that is not yet urbanised. Biryogo could be considered a poor area of Kigali city. The family was staying in small three roomed house for nine people. The head of the family was a widow (Jeanne) whose husband died of AIDS. She was unemployed. In addition to her own four children, she had her sister and two nephews as well as Jeanne's father. To survive, Jeanne made use of different people and institutions that support HIV infected people; including Mwana Ukundwa Association.

Only four family members were included in the study as the rest of the members were five young children (1-14 years) who did not know the infected family member's status. The case study was composed by the infected family member (Jeanne) - who is the head of the family.

Other family members involved in the case study were Beatrice, (Jeanne's first born); Aline, (Jeanne's sister); and Paul, (Jeanne's father).

#### **4.1.2.2 Case II**

The family was staying in Kivugiza area, Nyamirambo district, Kigali city province. This is a more urbanised area, and the family were living in bigger six roomed house for seven people. The family was headed by a widow (Marry). She was a professional, with full-time employment. She was a distant aunt of the infected family member. The family was supported by the income of the mother. However, the infected family member rented her father's houses and used the money from this to cover some part of her treatment.

Beside Mary's own child she was also looking after four orphans including the infected family member. The latter was an AIDS orphan, while the rest were orphans left by genocide in 1994. The four family members were Mary, the head of the family; Sue the infected family member, Christine and Diane, adopted children. Three family members were not included because two of them did not know HIV status of the infected family member, and the remaining family member who knew her status was not there at the time of data collection.

### **4.2 Findings of the study**

The findings of this study were analysed according to the theoretical framework, research objectives and questions. Based on this four themes were developed: stressors, family emotional reactions, coping strategies and effects of emotional reactions and coping strategies to the family infected member and family as whole.

#### **4.2.1 Case I**

##### **4.2.1.1 Stressors**

##### **Multiple losses**

HIV/AIDS infection was seen as incurable disease which was associated with loss of health and ultimate death. These losses were seen as stressors because they implied loss of the ability to work for the family, especially as the infected family member was the family breadwinner:

*“I reflected on the people who died with this disease in terrible state, even children, and I started thinking what was I suppose to do? I was troubled; especially when I considered that we already had no means (in terms of finances).” (Aline).*

*“When she has just told me...I started thinking how will it be if she died because she is the only parent we have... I used to be afraid of being an orphan in my young age (17 years)... We are all still children, where are we going to be? She is the breadwinner for the family, I would think, how were we going to survive” (Beatrice).*

### **Care demands**

Care demands were found as a stressor for the family. It was interesting to find that being sick was associated more with economic issues than the suffering of infected family member and care demands such as time to look after her. The family found it hard to meet care costs especially the special diet that the infected family member needed, as the family was struggling to get basic alimentation. Furthermore, being sick meant that the breadwinner would not be able to go out to work and provide for her family. Fortunately, in addition to free medical care provided by the public health system for HIV infected people; Mwana Ukundwa Association paid for her medical aid.

*“When she gets sick, she needs that stuff (type of food) that increases the blood, but we don’t have the means, we even get something to eat by chance. When she gets sick, I get worried,*

*she is the one who is able to provide for the family, ask myself what was it going to happen then? I always keep praying to God to protect her from getting sick. ” (Aline)*

### **Social demands**

Social demands were also perceived as a stressor more especially the day to day running of the home and the responsibilities that are involved in performing such a role.

### Family interaction

Parenting responsibility when Jeanne will not be there was seen a stressor to all participants.

It was interesting to note how each participant experienced this stressor. This depended on his/her position in the family and his/her capacity:

*“I felt that the fact that my mum was infected has given me as the first born the responsibility of looking after my young brothers when my mum dies. She is the only the provider of the family, I think, how we are going to survive. Again, I think how I am going to live better with my youngsters” (Beatrice).*

*“What worries me (grandfather) is that the children of these days, they don’t heed to the advice of their parents.” (Paul).*

*“I think about what I would do with children if she was gone, I don’t have a job I have nothing! When I think about this, I feel hurt and terrible inside me.” (Aline)*

Though the rest of participants reported their concerns about care of the children; the infected family member did not perceive their concerns and stress about the future of her children.

Jeanne’s assumption was based on the current family interaction.

*“It is only me who struggles for the family survival. Normally when you are sick you need to get rest, but for me it is not so, I have to struggle in this situation so that we get something to eat...to me this convinces me that when I am gone my children will die.” (Jeanne).*

### Stigma and discrimination

Stigma and discrimination was also reported as stressor for the family. This was related mainly to the meaning given to the infection and the fact that the infected family member was seen as being responsible for her infection.

*“I have contracted this disease and that was because I did misbehave. This may be one of my punishments. I deserve it...” (Jeanne)*

*“... some family members would pass the information saying that I was about to die with AIDS! They would say that am just dying, and more so dying with AIDS is shameful as one get the disease from adultery.” (Jeanne).*

The stigma and discrimination was also associated to the inaccuracy of HIV related knowledge such as ways by which the virus can be transmitted.

*“I didn’t even want her to touch my baby, because I was afraid that he may contract the disease...At the beginning, people wanted to isolate us, no one would ask for salt or anything even our children were avoided”. (Aline)*

### **Economic demands**

The data collected from the individual and focus group revealed family economics as the main stressor for both infected and affected family members. As it is shown in the case description, this was a poor family who were struggling to live, even before they found out that Jeanne was infected. In fact, Jeanne went for an HIV test so that she could qualify for help from the Mwana Ukundwa Association, which was providing support for HIV affected families.

*“Sometimes there is nothing to eat either lunch or supper, we just stay like that, and God sometimes does his miracle, and someone may come and leave us with something for the day...someone told me to go to Mwana Ukundwa Association to apply for my children's scholarships. So they told me they only accept the children for the parents who are HIV infected, then that is how I went for the blood test, I was found with it (HIV).” (Jeanne)*

The fact that Jeanne was infected helped the family get some support, which kept the family going:

*“She can just get here and there, and already some people know that she is infected by HIV so they help her. She is the only one who would get here and there to find those who could help.” (Aline).*

On the other hand, the infection worsened the family's economic situation, as Jeanne was the breadwinner. When she was sick, she could not go out to look for food. There are additional care costs too. The anticipated death of the family breadwinner was associated with anticipated economic problems when she passes away. It should be highlighted that economic demands were described as the primary stressor of the family.

*“...I would fall sick and fail to get something to eat for the family; they may be evicted from the house.” (Jeanne).*

*“I thought about the life, I considered that we already had no means (in terms of finances), what was going to happen if she passes away?” (Aline).*

#### **4.2.1.2 Family emotional reactions**

Participants reported a number of different emotional reactions. These were responses to the family stressors mentioned above. It was found that family emotions change over time; depending on what the family is going through. In some situations, emotions intensified whereas in others, the family lived as if this problem did not even exist.

##### **Shock**

Shock was reported as the first reaction to the disclosure of the family member's HIV status. However, in this study the shock was not accompanied with denial as usual, but with other emotions such as sadness and fear. This may be due to the fact that participants had suspected that the family member might have been infected prior to HIV testing.

*I saw her taking tablet and a friend of hers whom she had told about her status told me that she is infected. As she (infected family member) confirmed to me that she had been infected, I was shocked! I was so hurt.” (Aline).*

*When I got widowed I used to fall sick... then I went for HIV testing. At first when I got the result I was shocked, my heart started beating fast and I was afraid.” ( Jeanne).*

## Anger

The participants express their anger in different and implicit ways. This anger was accompanied with blame and hatred. The self-blame was reported by the infected family member. Some family members saw Jeanne as responsible for the infection, while others blame men.

*"I did not care for myself. Then I think if this happens, then this is one of my punishments. At times I would feel that this is what I deserve"*( Jeanne).

*"There was a moment when I thought that my child misbehaved."* (Paul).

*"When I look back and see the situation we are in, I consumed by hatred and anger for men in my life. Men can never be able abstain, they always keep lying and spread this deadly disease."* (Aline.)

Jeanne's anger was due to social stigma that considers infection to be shameful.

*"They would say that am just dying, and more so dying with AIDS a shameful disease as one gets the disease from adultery. When I meet with these people they look at me badly."* (Jeanne).

## Sadness and helplessness

Beside the sadness experienced as reaction to the HIV status disclosure; participants experienced sadness as result to other stressors such as stigma and discrimination and



anticipated death of the infected family member, which rendered the future unpromising in terms of family economics.

*“When, people wanted to isolate us, I would feel hurt and disappointed” (Aline).*

*“I was so saddened when I thought where I was going to leave my children” (Jeanne)*

*“I was so sad, because I would think this is only parent we are left with, what then our life would be if she dies? It makes me sad and thinking a lot about future life.” (Beatrice).*

The participants expressed feeling of helplessness. This was associated with the incurable nature of the disease and the HIV-related economic situation that family would be in when she dies.

*“It is worthless to be irritated about something that has already happen (contracting HIV infection) when you can not change It.” (Paul).*

*When we are with mom and encounter any problem, I would say in my heart, what are going to do if we encounter the same problem when our mom has passed away. We are all still young, there is nothing we can do to change the situation... there is no solution.” (Beatrice).*

Participants reported that helplessness affected their daily activities. The following statement of Beatrice described it:

*“I would at one point think about what our life was going to be in future. This has affected my studies since the same thought would jump in my mind and I would feel discouraged.”*

(Beatrice)

### **Fear**

Fear was common amongst participants. Despite the fear of dying, the participants expressed the fear of contracting the disease. They were also fearful of what their future may hold.

*“When I got the result, I was scared of dying in sin”. (Jeanne).* Jeanne thought that her infection was a punishment for her misbehaviour.

*“I realize it may also happen to me as they are some women, married and unmarried who had also contracted the disease. It was just confusing... At the beginning I didn't even want her to touch my baby because I was afraid she might pass the virus to him. (Aline).*

*“If she happens to be sick I get worried as she was the one who was taking care of the children, and providing food for me too. (Aline).*

### **Shame**

Shame was experienced on the part of the infected family member as she explained above that HIV/AIDS is a shameful disease that one got from adultery:

*“AIDS is shameful as one get the disease from adultery.” (Jeanne).*

#### 4.2.1.3 Coping strategies

Coping strategies employed by the family members could be placed into two categories. This includes coping strategies used to deal with emotions they went through (emotions-focused); and strategies used to deal with the stressors itself (problem-focused).

##### **Emotions-focused**

Participants reported different strategies they used to cope with their emotional reactions towards having a family member who is HIV infected. Defence mechanisms, avoidance, opportunity to talk, HIV-related knowledge, and different support systems were listed as strategies employed by the family.

##### Defence mechanisms

Participants of this study avoided thinking about the situation they were in, in an attempt to suppress their emotions. This was a way of trying forgetting their stressors.

*“I just avoid thinking about it; I would force myself to forget about it.” (Beatrice).*

Denial was also mentioned as coping strategy used to deal with unbearable emotions related to AIDS phase of infection. It should be highlighted that the AIDS phase not only involves physical suffering, but also economic and care demands that are already overwhelming. The statement of Jeanne illustrated it:

*“I never thought I was going to get seriously sick, God will not allow me to remain in this condition for long. I feel that one day I will die in my sleep.” (Jeanne).*

The rational explanation given as to what happened to their family member helped participants to go through HIV-related emotions and accept the situation. Paul reported:

*“There is no problem, this is meant to happen. Today it is her turn, probably tomorrow is me or anyone else. Every one has his/her destiny, some people's lives perish in car accident, others in something else, and I believe this is the God's plan.”* (Paul).

Humour was also reported as a strategy used to reduce the tension related to HIV-related stressors:

*“When you enter the house and you make people laugh, despite her illness you talk about it and laugh”.* (Paul).

#### Opportunity to talk

Participants reported that having opportunity to talk with people and share their concerns; helped them gain some emotional relief. Advice from significant others was seen as helpful:

*“When I talk to my friends (who are HIV infected) there are times when they would counsel me on how I have to handle myself. Sometimes when we are together I find comfort and I feel am not alone. We laugh and talk”* ( Jeanne).

Participants found also comfort from people who were not aware of Jeanne's HIV status. It was reported that just being with others and talking to them without disclosing their infected family member status had positive effects on their emotions:

*“At times when you chat to people, you find that are able to laugh with them and forget what was worrying you before...I would also talk to my friend, while she tries to encourage and educate me. But I have never told her whether my sister has contracted HIV.” (Aline).*

### Avoidance

Participants also reported using avoidance to any emotional-provoking situations that would remind them of their HIV/AIDS related experience:

*To get this out of my mind I avoid any situation that will bring me back this bad experience.”*  
(Beatrice).

### HIV related knowledge

Gaining knowledge from information sources regarding HIV/AIDS as well as other people's experience with this disease helped participants deal with related emotions.

*“At one point, I reflected back and realized that she was not the only one who was infected with diseases but there are many other people who were infected yet there were looking healthy.” (Aline).*

*“As the time goes by we continued to get informed about HIV, and we realized this is global issue”. ( Paul).*

### Spiritual support

Participants reported that believing in God helped them cope with their emotional reactions to the infection. Furthermore, the infected family member reported that her faith enabled her to face her anticipated death without fear:

*“When I knew that the disease was going to kill me, I started to worship God so that I would not die in sins. I ask God to forgive me and give me strength. I also look towards God to help me through all my problems... Even when I have to die, I must know that the one that I will be going to He who is powerful and his in new world.”* (Jeanne).

*“I would feel a moment of relief when we pray. As the bible says when you ask for something from God, and believe without doubt that you will get it, you will eventually get it, and this gives me relief”.* (Beatrice).

### **Problem focused**

Practical support offered when the family was going through a problematic time had positive effect on the family emotions. It is evident that when the problem was solved, these emotions were also reduced or eliminated.

### **Treatment**

Jeanne's health status was report as the major source of family emotion. Thus providing her with effective treatment was a useful strategy used to deal with this health related stressor.

Jeanne's recovery was seen as miraculous healing from God:

*“When she is not sick I consider that God has replied to our prayers, and then I become relieved and forget.”* (Aline).

Recovery was also achieved through effective health care. The fact that effective medicine i.e. antiretroviral drugs were becoming accessible to infected people in the country, was reported as source of relief.

*“We praise the Lord for the presence of the drugs that give relief, it is the will of God, that these drugs were discovered.” (Paul).*

#### Coping with economic demands

With regard to the economic problems that were also mentioned as one of the main stressors for the family, the family members, friends and Mwana Ukundwa Association work together in order to deal with this problem:

*“We don’t have any tangible income, we just live on subsistence farming, but these days I am trying different projects to see whether it may help in the future, also to create some saving for these children, because they are mine. I was a pensioner, but now I decided to look for a job again so that I can help.” (Paul).*

*“There are also other friends to our mom, who we also sometimes tell... others would help even if it is a little. There is also one Association (Mwana Ukundwa) that also helps, they give us food.” (Beatrice ).*

The infected family member reported that when the problem was solved, she felt emotionally supported:

*“One thing that makes me calm is when I know that we have something to eat and we are not yet to be evicted from the house; otherwise, the children are being paid for.” (Jeanne).*

#### **4.2.1.4 Effects of family emotional reactions and coping strategies to the infected family member and family as whole**

##### **Effects of family emotional reactions**

The effect of HIV/AIDS on the family's emotions and dynamics was reported by all participants. The family members were aware that their emotions affected other family members; especially the infected one.

*“When children that I am going through a bad patch, they become discouraged. If they realize that I am not happy and their mother is sick they just become cold and the long talks become over”. (Aline ).*

Consequently, an effort was made to hide their emotions in order to avoid negatively affecting others:

*“I try to cover my emotions and concerns from my family so that they are not affected in any way. I just ask her about how she feels, in the way she does not realizes that I am sad.” (Beatrice ).*

*“Showing her (infected family member) that I am depressed would be like adding salt in the injury.”( Aline).*



Hiding one's emotions was seen as if he/she did not care of what the infected family member was going through, showing one's concern meant the opposite on the part of infected family member:

*"At the beginning my daughter whom I had told about my status, seemed not to care ...but these days' things are okay, and she seems concerned and she sometimes asks me how I feel."*

(Jeanne).

Some emotions were seen as positive and would then have a positive effect on the infected family member as well as the family as whole:

*"When a sick person is not seen as an embarrassment or harassed and mistreated, she just feels okay and cared for. You have to show her love and concern, otherwise she will be discouraged, troubled and eventually she would feel being isolated. If you are not caring for her, she will be disheartened. When you find an old man (like me) caring and asking how she feels, alive and supported."* (Paul).

## **Effects of coping strategies**

### Effect of emotional focused strategies

Emotional focused coping strategies used by the family such as defence mechanisms, family relationships, avoidance, talking opportunities; HIV related knowledge and spiritual support had a positive effect on the infected family member as well as on the family as whole. These strategies helped participants to find some meaning in what happened to them and hence integrate it in their life:

*“We decided to accept it. This is like a cross that one must carry properly as it is in the God’s plan.” (Paul).*

#### Problem solving strategies

Coping strategies that focus on solving problems encountered by family were seen as having positive effects on the mental health of family and in particular, on the infected family member. These strategies included the treatment, and solving HIV related demands such as economic demands:

*“When she is not sick, I feel relieved and think positively... If there is a support you give to her, she becomes strong and encouraged as she feels that children are going to get something to eat.” (Aline).*

*“even when what she wants is not available, but she sees that we are trying hard to get it she gets encouraged...Like showing her how much we have and use it to solve any problem that may be prevailing, even if it is insufficient we just accept the situation and become strong.” (Paul).*

Despite effective emotional and other coping strategies reported by the family member, the infected family member perceived her family to be less supportive in terms of family finances. This had a negative effect on her emotional state and made her worry about her children’s future. She reported that she wanted to leave her children in an orphanage when she dies:

*“At the beginning I thought my family would help, but up to this point I just struggle all by myself. However, I have hope because Mwana Ukundwa Association is building a child caring centre, my children will have where to live”. (Jeanne).*

The lack of perceived support from the family in turn has affected the entire family. It induced negative emotional reactions on the part of the infected family member. Jeanne withdrawn and isolated herself from the family as part of her coping strategy in the situation. It was found that such strategies hindered family communication:

*“There are times I would be angry and do not feel like talking to anyone. When other family members try to ask what has happen to me, I just keep quite. They become confused troubled, and also keep quite too. I just reply in brief and very occasional”. (Jeanne).*

#### **4.2.2 Case II**

##### **4.2.2.1 Stressors.**

##### **Multiple losses**

Participants reported multiple losses as one form of stressors they experienced. Losses were stated in term of loss of health, death and loss of future plans. Loss of heath was related to the fact the HIV/AIDS was seen as an incurable disease; which they could not expect the infected family member to recover from. In addition, the infection was associated with endless suffering on the part of the infected family member:

*“You understand how worried I could be when she was very sick and yet I knew she will not recover from the sickness... But when you realise it is going to be an endless suffering, you also suffer with her but you don’t show it to her.” (Mary).*

In addition to the loss of health, death was anticipated. This was complicated by the fact that the family had already lost many members due to AIDS and to the genocide in 1994. Thus, the death of infected family member implied the complete extermination of the family, especially Sue's nuclear family:

*"Only a few days and I will die...I would remember that I am the one left in my family and after my death our family will be completely exterminated..." (Sue).*

Loss of future plans due to the infection by HIV was mentioned by some participants. This would be due to physical demands and care demands of the infected family member. These demands would affect future plans for infected family member as well as other family members:

*"I was upset because I was the eldest child and I knew I will have to be her caretaker. I felt my future was completely compromised. You look at her age, and you guess she could be planning for her future... up to now there is no cure for this disease and people keep on dying. Trying to comfort such a young person who should be making plans for her future like other girls of her age is not an easy matter. What can I tell her concretely to comfort her?" (Christine).*

*"But which job can you do when today you are in and tomorrow you are out because of illness?" (Sue).*

### **Care demands**

Caring for an HIV-infected family member was associated with a range of emotions. This was due to assisting her while she was enduring physical pain, and in particular suffering from

unusual illnesses. Emotions were increased by the fact that the family members thought that there was no solution for her physical state and felt helpless:

*“Maybe you could get some hope if you thought she is very bad now but at the end she will get any better. But when I realise that this great pain will never be soothed or end, I am definitely shaken. Then things became complicated when she started suffering from other diseases like vaginal infections. Things even old people do not know, you see them befalling to such a young kid” ( Mary).*

*“You feel so insecure because you know anytime a terrible sickness will strike and bring you down. Or you think one day everyone will turn his back on you and there will be no one to give you even a glass of water.” ( Sue).*

The lack of communication between family and health providers was also described as a family stressor. Participants reported that, for example the diet recommendations health care providers prescribed to the infected family member were unrealistic, considering to the Rwandans economical situation. When the family could not meet those diet recommendations, it created conflict between the caregiver and the infected family member:

*“Sometimes, health care providers can also create conflicts between infected persons and their caretakers or family members. For example, there is this one doctor who has told her what her diet must be. He said for lunch, she should eat meat and for supper this and that. Of course that is ideal, but you will not make me believe that even the doctor can afford such foods everyday in his family. You try to change the way you eat but within the limits of your means. They must be realistic! Because they care for infected people, they end up thinking*

*that is the only thing going on in life, but they must take into consideration the current economical situation.” (Mary).*

Caretaking requires time, and as participants had other activities, they could not provide the quantity of time needed to care for the infected family member. This was also a stressor for most of the family members:

*“I think that now the major problem is time. Medical follow-ups overlap on her class hours, and since it is a constant follow-up, everything else in her life seems to have stopped. The fact that I am not at home all the day is also a problem. I am pretty busy. One of my prayers to God is “O God help me so as to have much more time to spend with her, at least to talk with her.” (Mary).*

*“So, although we would like to stay and nurse her, we must go and work and she stays alone. On the other hand, there are times when you should be dealing with your own business but you are obliged to stay and care for her.” (Diane).*

At the beginning, care became stressful due to the infected family member’s belief and behaviour towards the care she was given. It was reported that believing in miraculous healing resulted in incomppliance with medical treatment:

*“She did not like the drugs in the beginning. It was tough to make her take them. She said she had a promise that God will heal her. Making her understand that God can fulfil this promise through medication was not an easy business and it took a lot of efforts from me, the family and friends to make her change her mind.” (Mary).*

Despite HIV-related information, participants also reported their fear that they would also be infected while caring for the ill family member:

*“I am not so sure I can live with someone so ill and not be infected, since we share the same bed. Sometimes, she had cuts, wounds or shingles on her legs and I really feared to be infected. But one day I went to see a doctor and told her about my worries. She told me there were very few chances for me to get infected in the circumstances I described. But I was not convinced. Even now, I am still afraid.”* (Christine).

### **Social demands**

The analysis of the social demands theme led to categorise the data in two sub-themes: family interaction and stigma and discrimination.

#### Family interaction

Having an HIV infected family member affected family interaction. Participants reported that the family interaction was altered partly by the behaviour of infected family member; which could be linked to her reactions on being infected by HIV:

*“Sometimes her attitude, behaviour and mood change and she becomes very quiet or indifferent depending on how she is feeling or what her thoughts are. In times like these, I feel hurt although she might be suffering at that moment. I told you she could sometimes look very indifferent and even ignore the basic rules of living in a family, like informing the other children when she was going out.”* (Mary).

The infected family member could not help in other family activities. In addition, caring for her was seen as an extra activity to those required in the absence of the ill person:

*"I could go to church and when I return home, she would have cleaned the house for me; I would deal with other domestic duties. But when she is sick, she even the little water available is for her alone."* (Christine).

Secrecy around the infected family member's HIV status was listed amongst family stressors especially before the HIV status of the infected family member was disclosed to the rest of the family. At this time, providing special care to the infected family member, would hint at unjustified favouritism to one family member. The rest of the family couldn't understand her behaviour, for example, not participating in household chores:

*"Of course it was worrying for me before the other children knew that she was infected, since I don't like to show a hint of favouritism to any of them. So, when for example we had some expensive food but in little quantity like milk, eggs or meat, I could not let her have it alone and ignore the other kids. In such circumstances, it was something that was agreed upon between us that if there was something special she needed; she would take some money (she owns some small houses that we rent out) and go and buy it. At those times they might also wonder why she did not help in domestic duties, but at the end they understand she is not able to do that and they accept that."* (Mary).

Lack of communication was also seen hindrance to family interaction. Emotional reactions were reported when family problems, especially related to caring for infected family member, were not properly shared between the rest of the family:



*“There are things which remain between us when we are chatting. For example, sometime I do not have transport money to go to the hospital and mother does not know it because she thinks I have money. That makes her sad...I have realised that keeping it to myself hurt some people so deeply.” (Sue).*

*“When she tells me nothing, I wake up and go to work as usual but she stays behind, hurting; because I’d supposed you still have money and yet you have already used it. And off I go with a non-guilty mind. Simply because I was not informed! Again, it revolves around the problem of time and communication. And sometimes you decide to speak out it is too late to do anything.” (Mary).*

### Stigma and discrimination

Stigma and discrimination associated with HIV/AIDS were mentioned as inducing emotions amongst family members. It was, however highlighted that only the infected family member experienced that stigma and discrimination. Besides the reaction of other people to the infection, self-stigma, on the part of the infected family member was also reported:

*“When I was still living at school, many schoolmates did not want to approach me or to be involved with me in any relationship. None would borrow a cup from me. Children in year one would not talk to me, as if they were afraid of me. At times I feel the old hurt come back. For example, yesterday I got my hair cut. I did that because people were saying my hair is becoming rare and unhealthy (because of HIV). When my hair becomes like this, you think you are done.” (Sue).*

*"It appears to me that it is rather herself who separates from others. When she learns that someone is suspecting or has said that she is infected, she is very angry and hurt. She thinks people go around gossiping about her. She would want to have an argument with them. There are times when people who know her ask about her and promise they will come to visit her. But when I report this to her, she is angry that we say she is ill. It appears like she wants to hide it". (Christine).*

### **Economic demands**

The economic demands became family stressors in terms of health care-costs and nutritional demands for the infected family member. It was also reported that the situation was complicated by the fact the family did have enough economic income as it is a big family headed my widow:

*"Look! I have no husband, neither have I anyone else to help me. I feel all alone to deal with this. Besides, I have some other orphans I have to look after. Now I work like everybody in Kigali does. I have to look after seven people... If I was well-off, I would always have good foods at hand and she would also benefit from it. But it is very expensive and I cannot afford it for seven people." (Mary).*

*"Before she'd started to receive free medication, the cost could reach up to 20000 Rwandan francs (35USA\$) and more. This amount could help the entire family but was spent only on one person. Her illness therefore affects the family budget...There are times when we come home and she cannot eat the food, in most cases there is no money to buy special food for her. In times like that, I often leave her and go to bed to cry. When she does not eat, her stomach aches and the view of this is indescribable." (Christine).*

Care-costs were seen as having an effect on the family and infected family member finances in general. This made their future appear unpromising:

*"It worries me very much because I realize that we throw a huge burden on mother's shoulders while she could be planning for the future of her own child too."* (Christine).

*"The rented houses that were giving money need renovations but I do not have money for that, because I have spent it on drugs and on goods of first necessity related to my illness... Maybe I could get into retail commerce or get a job. But which job can you do when today you are in and tomorrow you are out because of illness? I cannot think of any."* (Sue).

#### **4.2.2.2 Family emotional reactions**

Participants revealed going through different emotional reactions related to the reported stressors. It was stated that these emotions changed with health status of the infected family member. Sometimes participants could forget that one of their family members was infected; especially when she is not sick. Normal daily circumstance was also thought to have effect on the family emotional state:

*"You know, in her everyday life, a person is not always the same. Sometime, you can be easily irritated depending on how you are made. You cope with/accept events according to the mood you are in at that moment. When she is in a critical state, I am really hurt, very much hurt. But at other times, I feel I am used to it and I am not disturbed at all."* (Mary).

#### **Shock**

Family reactions to the infected family member status were closely associated to the information they got before the test and disclosure of the test result. Though her parents and brothers died of AIDS; the participants did not accept that she was also infected. Shock was reported by some participants as an emotional reaction to the diagnosis of the infection by HIV. In contrast the infected family member did experience this emotional reaction as she believed she was infected even before the test. This may be due to the preparation session for the test she had undergone and her health status, as she was sick at that time:

*“You know, when you are not sure yet, you still doubt and can still tell yourself maybe it is not AIDS. Doubt is just doubt, you are sure of nothing. But when I knew exactly what was going on, I was overwhelmed, dismayed.”* (Mary).

*“I then went to see a doctor and told him the way I was feeling. I showed him everything, including the infections in my vagina area. Although he told me to come back for a test (for HIV/AIDS), he added that there were more chances that I was infected. He asked me to be strong, no matter what the results would be. In fact, when I considered all the diseases I had suffered from, I realized that this was unusual and I was convinced of my being infected long before the results came out. I was not surprised at all by the test results”* (Sue).

## **Anger**

Anger was experienced by all participants. They directed their anger towards who they thought to be responsible of the infection. The anger against God was also reported, as the family continued to lose its members, in addition to those killed during the genocide:

*“I was angry against my father. Whenever I had a problem, I was fuming against him and I thought if he could come back I would be mad at him because it is him who brought AIDS in*

*the family and infected my mum. He was used to travel around because of his job. Mum always stayed at home with us. So I was cross because it is his fault that we all got infected and the other children died.” (Sue).*

*“On the other hand I have felt angry against God. I wondered why part of my family was exterminated during the genocide and the remnant was dying like this.” (Mary).*

Participants felt anger towards the stigma and discrimination associated with HIV/AIDS. This anger was directed not only towards the individuals but also to the institutions that support HIV infected persons for unfair selection of whom they support:

*“But when I hear people gossiping about my health problems, I get very angry.” (Sue).*

*“I am also cross towards the institutions that support HIV infected people. They always pretend that there must not be discrimination among infected people, but it is not true. When an infected person is not recommended by a known person to an association for support, he/she has no chance to get helped but to go and die. I think even infected people who are poor need to be looked after.” (Christine).*

Anger was also associated with the lack of communication between health care provider and the family. The family felt that care-related information should be discussed between the health-care provider and caregiver before being given to the infected person. If this was done without informing the caregiver, the infected family member would not feel cared for. This could be related to the fact that care was not discussed between the family head, health care

providers and the infected family member in order to reach the conclusion of why she should be better cared for.

*"I could feel very angry at times when I thought that people were not looking after me when they could've done that."* (Sue).

*"Telling such a thing (how she should be cared) to an infected person without discussing it previously with the caretaker! It has really annoyed me and I felt morally hurt."* (Mary).

### **Sadness and depression**

Physical suffering, anticipation of death, stigma and discrimination, inability to perform activities and hopelessness about the infected member's future were responsible for feelings of sadness and depression amongst participants.

*"Her sufferings touched me deeply. I felt sorry for her and especially when she cried, I would cry with her. I'd thought that having accepted it will make it look normal, but when I was crying, I could feel it was not normal."* (Christine).

*"It makes me sad when she is isolated or when her schoolmates gossip about her disease."* (Mary).

*"It hurts me not to do what others are doing or be where they are, but there is nothing I can do about it."* (Sue).

*"It is hard to find words for the whole thing. For a person so young... You see, when you are bringing up an orphan, you think to yourself "I am helping her to help herself in the future.*

*And you hope she will achieve a lot in life for herself. You hope that she will be there for you in times of need or just for looking after the little ones when you are no longer there. But instead, what do you get? You cannot help getting discouraged"* (Mary).

Participants reported going through an emotional state that can be considered depression. They felt discouraged, hopeless and useless. They experienced sleeplessness, crying and a lack of energy and motivation:

*"...Then she is really bad and starts vomiting... she is very low and you feel so helpless since you cannot do anything to ease her suffering and the pain. When you realise that this great pain will never be soothed or end, I am definitely shaken. I feel so helpless and useless"* (Mary).

*"Knowing that I, was infected, I felt lost and could not concentrate on studies. I would think 'why should I study. Only a few days and I would be dead, so why bother?' I could not study and when I tried I felt no strength or motivation to carry on and I would leave it. I could not sleep. Many thoughts flooded in my mind and they still do, mind you. I would remember that I am the one left in my family and after my death our family will be completely exterminated... I would withdraw decide not to talk to people anymore and that is what I did."* (Sue).

*I even cried and could not sleep, the whole night, when I thought about her situation.* Diane

## **Fear**

HIV-infected family member has already started to fall sick to some opportunistic disease. It was reported that those diseases provoked fear in both the infected family member and other

family members. The infected family member stated that suffering is more frightening than death:

*"The idea of falling sick scares me to death. I have been affected by so many tough diseases and they have caused so much pain that I am frightened of catching any of them again. I am scared of suffering. I do not fear death; I only pray that God gives me a happy end."* ( Sue).

*"... It was more feelings like anxiety and worries about the future, especially because you know that the worse is yet to come."* (Mary).

Having an HIV-infected family member was accompanied by the fear of the effect that the infection would have on the family in terms of care and family interaction. Before disclosing her status to other family member, it was thought that special care would be misinterpreted by other family members:

*"Of course it was worrying for me before the other children knew that she was infected, since I don't like to show a hint of favouritism to any of them."* ( Mary).

The fear of being infected while caring for the infected family member was reported by participants:

*"There are even times when she asks me to cut her nails and I have to do that even though I am always scared"* (Diane).

Fear was also reported as a response to stigma and discrimination that the infected family member had experienced:



*“When students in my new school began to suspect my infection, I was afraid that none among the students would talk to me, which they would run or keep away from me as in my former school.” (Sue).*

## **Shame**

Stigma and discrimination associated with infection by HIV/AIDS resulted in a sense of shame on the part of the infected family member. She explains in her following statement:

*“I would feel ashamed especially when I remembered how I had been discriminated and excluded in my previous school... I cannot take in all the gossips and I feel ashamed to walk in the street.” (Sue).*

### **4.2.2.3 Coping strategies**

Participants used both emotional and problem focused coping strategies to deal with their emotions and stressors respectively.

## **Emotional focused**

### **Defence mechanism**

Despite the opportunistic illnesses that the infected family member had experienced prior to her HIV testing, and knowing that her parents and siblings died of AIDS; participants could not accept that she was infected. However, the HIV test results removed this defence mechanism:

*“When she got into in secondary school, she started falling sick, shingles would come on her skin and I began to suspect she could be infected; but I could not stand accept it” (Diane).*

### Opportunity to talk

Sharing one's concern with somebody was one of the coping strategies that participants used to cope with their emotional reactions. Being able to disclose the HIV-status of the infected family member to other family members, as well as significant others, facilitated emotional mutual support within the family and from others:

*"It was a huge relief for me when we decided to let all the other children know about her sickness. Since she had known she is infected, she accepted that and even let other people know it; therefore my anxiety had subsided. We both talk about and it gave me an opportunity to comfort her and actually to cope with it myself."* (Mary).

Participants reported sharing HIV-related emotions with other family members as well as significant others in order to cope with their emotions:

*"I never did things like shouting or tell to people around me what I was going through. I talk about this with only one lady who is my neighbour and she gives me some moral support. I also talk to my brother"* (Mary).

*"When it becomes unbearable, I go and talk to mother. I also keep chatting with her when she is ill."* (Christine).

### Positive self-encouragement

Participant reported using positive self-talk when facing emotions associated to HIV. This included self-encouragement as illustrated in the following statement:

*"I am really afraid and hurt when it comes to taking drugs and injections because I know she is suffering too but I try to convince and encourage myself that little by little, all this will end."* (Mary).

### Distraction

It was found that family member used different ways of distracting themselves as a coping strategy to deal with their emotional reactions. This included listening to radio and gospel music, as well as sleeping:

*"I also like to listen to the radio. When something bothers me, I listen to some gospel music and I feel like forgetting the matter which was troubling me."* (Sue).

*"One thing I try to do is sleeping and finding some rest, and it helps me to forget."*  
(Christine).

Opposite strategies such as active attending and thinking at one's emotions were also found to be an effective strategies to reduce the emotions:

*"I sometimes take time and think about it and it reduces my fear and worries."* (Diane).

### Spiritual support

Spiritual support was reported as an effective strategy to cope with the infection related emotions for both the infected family member and the rest of family members. This spiritual support involved being with other Christians and receiving comfort from them through prayer and sharing emotions. Such support would not only encourage her faith but also it might provide her with socio-psychological support. The infected family member reported that her relationship with God helped her to ease her emotions, despite the problems she experienced.

Faith helped her to face the anticipated death without fear, as she associated her death with the fulfilment of God's purpose in her life, rather than the infection.

*"I am in touch with so many men and women of prayer, I briefed them about my health and they pray for me, comfort me and help me to cope. Prayer helps very much. Only prayer gives me peace and I am not afraid of the death, although I know I cannot die before God has fulfilled His purpose for my life."* (Sue).

*"All this convinced me that God who has taken her this far can do even more for her. So, my pain is slowly subsiding and I have now come to a point where I can accept what is happening to her."* (Diane).

#### Withdrawal behaviour

When participants were going through overwhelming concerns they tended to withdraw into themselves and not share their concerns with anyone. This coping strategy was seen as ineffective as it increased negative emotion.

*"When the pain becomes really deep, I take it all inside me and keep quiet... something so desperate and with no solution... I do not know. I might wake up in the middle of the night, think about this ordeal and lose my peace of mind. That is all".* (Mary).

#### Use of alcohol and attending nightclub

The use of alcohol and going nightclub were used to ease the infected family member's emotional reactions and to get to sleep at night. This coping strategy was also reported as ineffective as described in the following statement:

*“...I started drinking very much and going out in nightclubs as I could not sleep. I thought I would find some kind of inner peace in doing that. I would follow my pals in nightclubs and drink a lot so that I could sleep. It was like taking drugs. I would go in the dancing clubs or drink to try and forget what I was going through.” (Sue).*

### **Problem focused**

#### Treatment

Strategies that used to improve the infected family member's health status had an indirect positive effect on participants' emotions. Participants considered improvement of the health status of the infected family member as a result of effective health care services timeously sought, the availability of anti-retroviral drugs and healing from God:

*“I tell her that she must go to the doctors as soon as she realises she's got any illness even though we do not have much money.” (Mary).*

*“Of course it has improved since then, especially since she has begun the treatment (anti-retroviral drugs).” (Diane).*

*“When I fall sick, I pray and the illness heals and I feel so grateful to God for the healing.” (Sue).*

#### Family interaction

Family interaction was reported as an effective mean to deal with HIV infected difficulties that the family faced. This involved helping the infected family member when she was sick as well as privileging her when needed:

*"...From that day on, the other children take care of her. The other girls help her in matters like hygiene when she cannot do it herself... As a family we are morally supportive. And if she has a need that must be met immediately, we agree to take some money from the next day's shopping. If there is milk or meat in little quantity, they leave it for her and the youngest child. But it is not always easy to find the right balance between her illness and the family finances."* (Mary).

Communication was reported as important strategy to facilitate family interaction. Through communication, participants could find a practical solution to any HIV-related problems the family encountered.

*"We are not too many in the family and we all have to live together. If something bothers me, I say it and we look for a solution together. So, I do not feel alone in my sufferings."* (Christine).

Communication was also found to be important when dealing with the infected family member's emotional and behavioural reactions to her infection. Open communication was used to try to encourage her to continue getting involved in family activities according to her capacity, treating her in the same manner that the other members were treated:

*"Sometimes her attitude and mood change and she becomes very quiet or indifferent depending on how she is feeling or what his thoughts are... I try to tell her off because I think*

*she must not withdraw completely from life as if she is already dead. I give her remarks as I do with other children. I ask her to do some easy tasks when she is not very sick. Honestly, I want her to be more active in what he can do. I believe this is more helpful for her than letting her feel as someone who is completely unable and who has no place among the other children.” (Mary).*

Passive withdrawal behaviour on the part of some family members hindered family communication. This coping strategy was adopted as to avoid being so demanding to the family and therefore reduce the mother’s burden. However, this was reported as an ineffective strategy.

*“At times, I feel like going and tell her whatever I need whether she would have a solution or not and then I feel sorry for her because she has to look after for the whole family. But I guess I have to learn to be like a child and speak my mind out even if I can not have everything I am asking for”( Sue).*

*“When she tells me nothing, I wake up and go to work as usual but she stays behind, hurting; because I’d supposed you still have money and yet you have already used it. And off I go with a non-guilty. Simply because I was not informed!” ( Mary).*

### Coping with economic demands

Participants reported working together to meet their economic demands related to having a HIV infection. Beside the monthly salary of the mother, and the rent of Sue parents’ houses; other family members used their hands to do family chores that would be done by a hired person. In so doing, the money that would be spent on those chores can be used for other things including caring for infected family member. In addition, it was reported that family

get some support from significant other and institutions that support HIV infected people, especially in terms of care-cost:

*“Since I have no money, I use my hands and do the domestic tasks, which normally would have cost money. That is the only way I can help. A relative of ours also helps us and when she buys her drugs herself, sometimes the money is refunded by Mwana Ukundwa Association.”* (Christine).

*“Before these anti-retroviral drugs were available, things were pretty hard but I always managed to take some money from my wages and buy her drugs (anti-retroviral drugs). And I’d tell myself that when I will no longer be able to do that, what would happen will happen! But God has been merciful. I had bought the drugs for only three months when someone who knew he was sick came and tell me there was a project within Kigali Hospital Centre, which provided anti-retroviral drugs. By the end of the year, she was listed on the roll and started the treatment.”* (Mary).

#### **4.2.2.4 Effects of family emotional reactions and coping strategies on the infected family member and family as whole**

##### **Effects of the emotional reactions**

It was reported that the individual emotional reactions of each family member had effect on the rest of family. In this case, participants were more affected by suffering and the emotional state of the infected family member. It was interesting that her suffering and subsequent related emotions also affected family members who were not aware of her HIV status.



*"Having an infected person in your family is like having one of your limbs sick. When one limb is not well, the whole body suffers." (Christine).*

*"However, sometime when she falls sick, she is very much afraid and does not want to sleep alone. This scares me and the other children. Even the little child (who is not aware of her status) feels it when she is not well... Sometimes her attitude and mood change and she becomes very quiet or indifferent depending on how she is feeling or what her thoughts are. In times like these, I feel hurt." (Mary).*

*"Sometimes she gets very angry for no reason and you wonder what is happening. At times I feel guilty, thinking I am the one to be the cause of her anger; at other times I simply ask her what is going on!" (Diane).*

Participants held different perspectives on the effects of their emotions on the infected family member. On one hand, it was thought that the emotional reactions of family members would have negative effects on the infected family member's emotions. Thus an effort was made to hide one's emotions:

*"I have never showed her that I was ever discouraged. If I'd done that, she'd have been even more desperate. Otherwise, if she suspected I was giving up, she would have felt abandoned, unsupported. You keep telling her to be strong, to be strong." (Mary).*

Others felt that family emotions would be a sign of their compassion to the infected family member, and therefore have positive effect on her. In fact, this viewpoint was in line with how the infected family member experienced the family emotional reactions:

*“When she is suffering, she knows I share her pain, so she can confide in me. There were even times in the beginning when I would cry and she was the one to comfort me and told me she has accepted her situation. Instead of discouraging her, my feelings comfort her. She can see I do not reject her, that I am compassionate when she is suffering. We feel really close to one another and this feeling is very encouraging for her.”* (Christine).

*“They are very compassionate and that makes me happy. You know, if you have an illness like this and you are surrounded by people who do not care, you would not feel happy, would you? When I am ill, they are also very anxious and afraid for my life.”* (Sue).

### **Effects of coping strategies**

#### Emotional focused coping strategies

Coping strategies such as defence mechanisms, opportunities to talk, distraction positive self talking and spiritual support all had a positive effect on the infected family member and family as whole.

*“The fact that family members and friends know about my infection helps me to be more relaxed and communicative. Thus, whenever I fall sick, I tell them how I feel and they can put up with my situation. Before they knew it, I could feel ill, leave the school to go home and they would insist that I return to school. Of course I returned to school but very reluctantly. You can see that everybody within the family is compassionate.”* (Sue).

The following statement illustrated the effect spiritual support had on the infected family member:

*"When I am praying, I can avoid these kinds of things; even gossips do not disturb me and whatever food I eat, I feel content." (Sue).*

Encouraging the infected family member to get involved in family chores was reported as having positive effect on the infected family member's emotions, as Mary reported when she was explaining why she encourage Sue to became active:

*"It is all about not losing your heart and knowing that you still have your worthiness as human being as long as you are alive." (Mary).*

Some coping strategies such as emotional withdrawal, use of alcohol, going to nightclubs were seen ineffective and having a negative effect on the family:

*"I have realised that keeping my concerns to myself hurt some people so deeply." (Sue).*

*"Actually, I came to realize that the peace I was craving for was not where I was looking for it (usual of alcohol and going to nightclubs)." (Sue).*

#### Problem focused coping strategies

Family interaction that was mainly facilitated by open communication had considerable effect on the infected family member, as well as the rest of the family. The positive effects of communication were reported as follows:

*"We sometimes talk about her situation, especially mother and me. At times, when I convince mother to give her some money to buy milk, I feel relieved. There is nothing else I can do; but when I see that she is relaxed, with no pain; I feel happy too." (Christine).*

When passive withdrawal behaviour was used, and the family could not communicate effectively, it had a negative effect on the family's emotional health and care of the infected family member. The following statements describe how lack of open communication affected the family:

*"I also think that communication is a key and I do feel guilty sometimes (when she is quiet). You kind of think you are not caring for her enough or you have said something should not have said. But when someone opens up to you and tell you the truth, you try all you best to help and get rid of your guilt."* (Diane).

However the infected family member reported that her silence did not have anything to do with them or the care she received:

*"They told you that I am often quiet, but the reason is I feel I don't have anything to say and I prefer to remain silent. I do not know how this happens and it has nothing to do with the fact that they do not care for me."* (Sue).

Related to this, participants emphasized the importance of communication between them. It was asserted that family communication, similar to what was facilitated by the research focus group, would help the family to improve their interaction in terms of caring for the infected family members:

*"It would be helpful to have occasions like this and talk through these problems. I do not know if any of us can think about it and organise something like this; but to be honest, I always wish to know what Sue thinks...I would appreciate her telling us all the truth, whatever she needs or anything wrong we do to her."* (Christine).

*“Communication is very important, between the ill person and caretaker so that there will be no misunderstanding. So that she will not feel as she was not cared for and on the part of the caretaker, she may not feel like everything is ok, while it is not.” (Mary).*

Participants mentioned that practical solution to the stressors such as economic demands had considerable effects on both infected and affected family members as illustrated in the following statement:

*“There are times when she falls sick whereas she has no money, If I lend to her the amount she needs, she is very happy. Some other times, I ask her what she'd like to eat and I cook it for her, and she is really delighted... when she get what she wants, I feel relieved.” (Christine).*

#### **4.2.3 Cross-case analysis**

Cross-case analysis was done to identify the similarities and differences between the two cases. The researcher analyzed how each theme was reported in both cases.

##### **4.2.3.1 Family stressors**

In both cases the family stressors included multiple losses, care, social and economic demands.

<b>Stressors</b>	<b>Case I</b>	<b>Case II</b>
Multiple losses.	<ul style="list-style-type: none"> <li>• Loss of health and death therefore loss of income as the infected family member is the family breadwinner.</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of health and death, thus family decimation.</li> <li>• Loss of future plans.</li> </ul>
Care demands.	<ul style="list-style-type: none"> <li>• Care-costs.</li> <li>• Sickness: the family breadwinner</li> </ul>	<ul style="list-style-type: none"> <li>• Care-costs.</li> <li>• Emotional and physical</li> </ul>

	could not go out to look for food.	suffering of the infected. <ul style="list-style-type: none"> <li>• Lack of enough time to care for her.</li> <li>• Acquiring the infection while caring.</li> <li>• Lack of communication between family and health care providers.</li> </ul>
Social demands.	<ul style="list-style-type: none"> <li>• Stigma and discrimination of the infected family member and family as a whole from community.</li> <li>• Self-stigma.</li> <li>• Family interaction: <ul style="list-style-type: none"> <li>▪ Stigma and discrimination of the infected family member from family other members.</li> <li>▪ Taking over of parenting responsibility when the infected family member dies.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Stigma and discrimination of the infected family member from community.</li> <li>• Self-stigma.</li> <li>• Family interaction: <ul style="list-style-type: none"> <li>▪ Emotional and behavioural reactions.</li> <li>▪ Inability of the infected family member to participate in family activities.</li> </ul> </li> </ul>
Economic demands.	<ul style="list-style-type: none"> <li>• Care-costs.</li> <li>• Decrease of income of the entire family.</li> </ul>	<ul style="list-style-type: none"> <li>• Care-costs.</li> <li>• Decrease of the income of infected family member only.</li> </ul>

**Table 2: Family HIV/AIDS related stressors**

Multiple losses imply death and loss of health, as the HIV infection was regarded in both cases as an incurable disease. However, the meaning of these losses of health and death meant different things for the participants. According to Case I, loss of health and death was associated with family income, as the family would lose its breadwinner. In Case II, losses meant suffering as well as loss of family member. In Case II loss of the infected family member meant the decimation of the entire family, as Sue's parents and brothers had died of HIV/AIDS; but also members of their extended family were killed during the genocide in 1994.

Only loss of future plans for infected family member and other family members was reported in Case II. The economic situation in Case I prevented them from making future plans, as their priority was meeting their daily basic needs; such as food and maintaining the rented house.

Care demands were also reported in both cases as a family stressor. In both cases, care demands were associated with care costs. In Case I, beside the cost of care, when Jeanne was sick, it becomes a stressor for the family, as she could not go out to look for food for the family. In Case II, care demands as a stressor was primarily associated with emotional and physical sufferings of the ill member and the lack of time to care for her. They were concerned of the possibility of acquiring the virus while caring for her as well as the lack of communication between the health-care providers and the family.

Stressors associated with social demands in both cases included stigma. Both HIV infected participants experienced stigma and discrimination. Self-stigma was also reported in both cases. Case I experienced stigma not only from the community members, but also from her own family members. In Case I, the entire family was stigmatized and discriminated by community; whereas in Case II, only the infected family member experienced stigma and discrimination.

Parenting responsibility was reported only in Case I in which the infected family member is in a parent position. In Case II, emotional and behavioural reactions; lack of participation in family activities on the part of the infected family member and secrecy around her HIV status was seen as hindrance of family interaction and therefore a stressor for the family.

Economic demands in terms of care costs for infected family member were considered stressors in both cases. It was reported that having an HIV-infected family member had created additional economic demands on both the families. HIV/AIDS had effect on the family income in Case I, where the infected family member is the breadwinner. It only affected the income of the infected family member in Case II because she was not the family breadwinner. Her own income was affected in the sense that the money she got from her rented houses was used for treatment. As result, the houses were dilapidated as she could not maintain them.

**4.2.3.2 Emotional reactions to the infection and related stressors**

Case I	Care II
Shock	Shock
Anger	Anger
Sadness and helplessness	Sadness and depression
Fear	Fear
Shame	Shame

**Table 3: Emotional reactions experienced by the family**

Both families experienced shock, anger, sadness, helplessness, fear and shame as responses to the above mentioned stressors. Depression was only reported in Case II, where the infected family member had reached the AIDS phase. This would reinforce the anticipated death that it precedes. In addition, the family had already lost many family members to AIDS and the genocide in 1994.

Fear was common in both cases, and it was associated with the fear of contracting the infection, as well as stigma and discrimination. Beside this, in Case I, fear was mainly linked



to economic insecurity. In Case II, fear was mainly as associated with the physical suffering of the infected family member.

In both cases, anger was associated with stigma and discrimination related to HIV/AIDS. It was interesting to find out how the anger was directed towards different people in the two cases. In Case I, anger was directed to the infected family member for misbehaving, and also to men for spreading the infection around. In Case II the anger was directed towards, Sue’s father who was thought to have brought the infection into the family. Participants in Case II were also angry towards God, who seemed to have forsaken them through the loss of other family members to through AIDS and the 1994 genocide. Anger against the lack of family involvement in a health care plan by health professionals was also reported in Case II.

**4.2.3.3 Coping strategies**

Coping strategies	Care I	Case II
Emotional focused strategies	<ul style="list-style-type: none"> <li>Defence mechanisms:               <ul style="list-style-type: none"> <li>Denial</li> <li>Suppression</li> <li>Rationalization</li> <li>Humour</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Defence mechanism:               <ul style="list-style-type: none"> <li>Denial</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• Opportunity to talk mainly with an outsider</li> <li>• Avoidance</li> <li>• HIV-related knowledge</li> <li>• Spiritual support</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity to talk mainly with family members but also with an outsider.</li> <li>• Positive self-encouragement</li> <li>• Distraction</li> <li>• Spiritual support</li> <li>• Emotional withdrawal</li> <li>• Use of alcohol and attending nightclubs</li> </ul>
Problem focused strategies	<ul style="list-style-type: none"> <li>• Treatment : medical care and healing from God</li> <li>• Family interaction <ul style="list-style-type: none"> <li>▪ To meet care and economic demands</li> <li>▪ lack of communication</li> </ul> </li> <li>• Socio-economic support from significant others and Mwana Ukundwa Association</li> </ul>	<ul style="list-style-type: none"> <li>• Treatment: medical care and healing from God</li> <li>• Family interaction <ul style="list-style-type: none"> <li>▪ To meet care and economic demands</li> <li>▪ communication was used to facilitate the interaction</li> </ul> </li> <li>• Socio-economic support from significant others and Mwana Ukundwa Association.</li> </ul>

**Table 4: Coping strategies**

In both cases, emotional and problem-focused coping strategies were used. Emotional-focused coping strategies included defence mechanisms such as denial which was reported in both families. In Case I, denial was used to deal with infection related emotions such as the progression of the infection to AIDS; whereas in Case II, it was used only before the HIV diagnosis was made. In Case I, other defence mechanisms including suppression,

rationalisation, and humour were used to deal with emotional reactions that were related to having a family member who is infected.

Having an opportunity to talk was one of the effective coping strategies used in both cases. Being able to disclose the HIV status of the infected family member was seen as the key to the emotional support from others. Participants reported the positive effects of talking; either explicitly HIV related concerns; or just having a normal talk with other people and implicitly expressing their concerns without disclosing the status of the infected family member.

In both cases, it was reported that having faith in God had a positive effect on the participants' daily HIV-related emotions. Furthermore, it was mentioned that faith helped both infected family members to face death without fear. In Case I, death was seen as a transition to a new earth; whereas in Case II death was associated to the fulfilment of life's purpose on earth, rather than a disease.

In addition to these common coping strategies, it was reported (in Case I) that avoidance, normalization, and HIV-related knowledge reduced the participants' emotional reactions. In Case II, positive self-encouragement and distraction resulted in a positive effect on their emotions. Some ineffective coping strategies were used; such as emotional withdrawal, use of alcohol and attending nightclubs.

Problem-focused coping strategies, such as treatment, family interaction, socio-economic support from significant others and Mwana Ukudwa Association were reported in both cases.

Treatment included the availability and accessibility of effective treatment such as antiretroviral drugs as well as healing from God. Family interaction was seen as an important

strategy to deal with HIV related problems. Participants in both families revealed that family members worked together to try and save money towards the care of the infected family member and the running of the house. Family interaction involved also taking turns to look after the infected family member. In Case II, one these interactions were facilitated by communication, whereas family members in Case I, seemed to lack open communication. Despite everyone’s effort the infected family member did not perceive them as supportive. In both families, it was found that a failure to share one’s concerns; resulted in negative effect on family members and their interaction. Significant others such as relatives, friends and people and professional at Mwana Ukundwa Association were regarded as a family support system.

**4.2.3.4 Effects of family emotional reactions and coping strategies on the infected family members and the family as whole**

Effects	Case I	Case II
Effects of emotional reactions	<ul style="list-style-type: none"> <li>Family emotions were mainly influenced by emotional state of the infected family member.</li> <li>Showing concern and care had a positive effect on the infected family member</li> <li>Anger, unhappiness, hopelessness and hiding one’s emotions had negative effect on the family’s emotions</li> </ul>	<ul style="list-style-type: none"> <li>The infected family member’s physical and emotional state influenced family emotions.</li> <li>Showing concern and care had a positive effect on the infected family member.</li> <li>Anger on the part of the infected family member had negative effect on other family members</li> </ul>

Effects of coping strategies	<ul style="list-style-type: none"> <li>• Problem solving had positive effect to the infected and other family members.</li> <li>• Lack of perceived support from family had a negative effect on the infected family member and the whole family.</li> <li>• Lack of communication had negative effect on the entire family.</li> </ul>	<ul style="list-style-type: none"> <li>• Problem solving had positive effect on the infected and other family members.</li> <li>• Communication was an effective strategy used to solve family problems.</li> <li>• Withdrawal behaviour affected family communication and had a negative effect on the entire family.</li> </ul>
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**Table 5: The effect of family emotions and coping strategies**

### **Effects of emotional reactions**

Emotional reactions of each family member had effects on other family members. In both families, the infected family member was the centre of emotional reaction as how she feels will affect the entire family. In turn, the family responses towards his/her emotions will also affect family members.

In both cases, positive effects were associated with being concerned with the infected family member problems, caring and compassion. Emotional effects were related to anger, unhappiness, hopelessness and hiding one's emotions in order to prevent any negative emotional influence to the rest of the family.

### **Effects of coping strategies**

In both cases, when HIV-related problems such as health status of the infected family member; care and/or economic demands were solved, and, at least when everyone tried to find a solution; this had a positive effect on the infected family member and the family as entire. However, in Case I, the infected family member did not perceive the family support in

terms of economic demands which had negative effect on her. In Case II, the family communication was effective in redressing emotional and behavioural reactions of the infected family member. In both cases lack of open communication had a negative effect on both the infected family members and their families. In many cases, this communication was hindered when participants used withdrawal behaviour as a coping strategy.

## **CHAPTER FIVE**

### **DISCUSSION RECOMMENDATIONS LIMITATIONS AND CONCLUSION**

#### **5.1 Introduction**

This chapter is divided in four sections namely; discussion of the findings of the study, recommendations, limitations for the study and a conclusion of the study.

#### **5.2 Discussions of findings of the study**

The sample of this study was from two families; one in which the infected family member was the mother; and head of the family (Case I); and a young person in position of a child in her family (Case II). As the HIV status of the infected family members was not disclosed to all family members (especially young children), the latter were not included in the study. It should be remembered that during sampling, the group of children were not included as they were unaware of their HIV status. In some families, the mother had hidden the child's status due to fear of stigma and rejection of the child. In their studies, Waugh (2003) and Beverley et al (2001), reported that parents of HIV-infected children partly disclose to the children their status without naming the infection. They also tend to delay the full disclosure in order to prevent them from the perceive hardships that this knowledge may bring, and the possibility that these children may disclose their status to other people.

##### **5.2.1 Family HIV related stressors**

In answering the question on HIV/AIDS related stressors that affected families experience; four main categories of family stressors were revealed. The categories are: multiple losses, care, social, and economic demands related to HIV/AIDS.

In this study, it was found that multiple losses included loss of health and death of the infected family member, as the HIV infection was seen as an incurable disease. The loss of a family member in Case I, meant primarily the loss of family income. This was due to the fact that the infected family member was the family breadwinner. In addition, the family in Case I was poor, prior to the infection. In Case II, loss of health and death of the infected family member were more associated with the family decimation, because the infected family member was the only remaining member of her nuclear family. The rest of her family had died of AIDS. Siegel and Gorey (1998), state that it is not unusual that a family lost more than one member as HIV infection can be transmitted to one's partner/spouse and children. They argued that such multiple losses in a family are emotionally taxing even if those losses are just anticipated. In addition to this, in Case II most of members of this extended family were killed in the 1994 genocide. A loss of future plans such as employment or financial improvement was reported in Case II. Studies conducted in the United States of America amongst gay males (Mallison, 1999) and people who live with HIV infected people (Cody, 2000), reported loss of life, family members and employment as stressors associated with a range of emotional reactions.

The study revealed that care demands in terms of care costs were also seen as stressors in both cases. Melnyk et al. (2001) report that the financial burden of ongoing care is a major stressor for the family. This was truer in Case I, where caring meant more financial demands than the suffering of the infected family member; was the situation in Case II. In Case I, when the infected family member was sick, participants were mainly stressed; not only for her special diet but also that she could not go out and find food for the family. Lack of emotional concerns on the suffering of the infected family member might be explained using Maslow's



Hierarchy of Needs (Gwynne, 1997). Here, physiological needs such as food are supposed to be met before other needs may be attended to.

In contrast, in Case II, stressors in terms of care was primarily associated with the emotional and physical suffering of the ill family member; lack of enough time to care for her; the possibility of acquiring the virus while caring for her; and lack of communication between the family and health care providers. Lesar and Maldonado (1997), Melnyk et al. (2001), Nyblade and Fied-Nguer (2001), and ICRW (2002), reported that caring for someone with emotional and physical pain, the time required for caring, fear of the acquiring the infection, lack of collaboration between caregivers and health care providers; can be experienced as stressors for caregivers. The differences between the two cases could be related to the different position of the infected family members in their respective families; family economic means and the relationship between members of each family.

According to the conceptual framework of UNAIDS (2002b), self-stigmatization or shame amongst HIV infected people is seen as a result of internalized negative responses and reactions of others to the infection. Chapman (1998), explains that stigma influences how HIV infected people see themselves. It leads to low self-esteem and a lack of self-worth. It was interesting to find that the infected family member in Case II, who acquired the infection from her parents, experienced self-stigma, because no matter where she got infection from, it is seen as shameful disease associated with misbehaviour. In his study amongst HIV infected people, Chapman (1998), reported that HIV infected people may believe that they deserved what happened to them. These findings are in line with the result of this study. In Case I, the infected family member reported that her infection was result of her misbehaviour.

In Case I, the infected family member experienced stigma and discrimination from her family. These reactions can be explained by the fact that the infected family member is said to be responsible for her infection. In addition to that, inaccurate information about HIV/AIDS as well as the relationship between family members could also be associated by the stigma and discrimination in this family. These findings are in line with those reported in study conducted in Uganda (UNAIDS, 2001a), Botswana, Zambia (Nyblade & Field-Nguer, 2001) and Tanzania (ICRW, 2002). In these studies, stigma and discrimination from one's family were associated with the ignorance in respect of HIV/AIDS, and also misbehaviour on the part of the infected person.

According to Case I, the family as whole was stigmatized and discriminated against by the community due to the fact that her children might also be infected during birth. Similar results were reported also in Uganda (UNAIDS, 2001a). In Case II, only the infected family member experienced stigma and discrimination, since she was an adopted child and therefore not related by birth to the family. These differences may also be associated with the fact that stigma and discrimination was reinforced by how the HIV infection was acquired. In Case I, the infected family member was said to be responsible for her infection; whereas in Case II the participant acquired the infection from her parents. Issiaka, Cartoux, Ky-Zerbo, Tiendrebeogo, Meda, Perre, and Dabis (2001), and Chapman (1998) confirms that stigma and discrimination are related to how the infected person acquired the disease. Stigma and discrimination are influenced and reinforced by negative thoughts and information that always links HIV with prostitution and multiple sexual partners.

Family stressors related to social demands included parenting responsibility as in Case I in which the infected family member is a parent. This finding was in line with the results of

Canadian study amongst HIV infected people (Beverley et al., 2001); which revealed that participants were concerned about who is going to look after their children when they die. Ingram and Hutchinson' study (1999) revealed that mothers believed that a child always needs a mother and there is no substitute for a mother. They may anticipate horrible things that will happen to their children when they are no longer there. In fact, the infected family member in Case I; despite the parenting concern of all participants; felt that her children will die if she is not there. Other family members in Case I, reported the taking over parenting as a stressor. Everyone would feel this responsibility once Jeanne passed away. Foster and Williamson's study (2000) that reviewed literature on the impact of HIV on children in sub-Saharan Africa, found that children start parenting responsibility even before their parents pass away. The same study also revealed that parenting responsibility may also fall on members of the extended family such as grandparents.

In Case II, family stressors were also associated with emotional and behavioural reactions, lack of participation in family activities on the part of the infected family member that hindered family interaction. Negative emotional and behavioural reactions are not uncommon amongst HIV infected people especially if they are still on the anger phase of the grieving process (Kaplan & Sadock, 1998).

Findings of this study suggested that the economic demands related to HIV infection in terms of care costs and lack of productivity on the part of the infected family member, are stressors to the affected families. Economic demands became a main stressor for Case I, where the infected family member was the breadwinner. The infection affected the source of family income. The major economic demands on Case I might also be due to the low-income of the family even prior to the infection. It should be remembered that having an HIV-infected

family member in Case I, helps the family to survive as she qualifies for support from Mwana Ukundwa Association. These findings are in line with results of a Ugandan study (UNAIDS, 2001a), in which participants assert that a positive result can give them access to service and financial assistance. An HIV-negative poor family would struggle to get this financial assistance on their own. These findings may explain the high prevalence of HIV-infected persons amongst poor people because a positive result has some positive effect on their economic situation. In their study Koopman et al (2000) and Beverley et al (2001), found that the low income of a family affected by HIV/AIDS was a stressor for participants in both studies. The findings of this study also supported the finding of another study conducted in Rwanda (UNAIDS, 2001b). This study reported that HIV/AIDS related economic demands is an additional economic problem to the majority of affected families that already find difficult, if not impossible, to find food.

### **5.2.2 Emotional reactions to the infection and related stressors**

Family emotional reactions to the HIV infected family member was defined as a component of the family mental health. In this study, it was found that emotional reactions to the HIV related stressors included shock, anger, sadness, helplessness, depression and fear and shame.

In this study, family emotional reactions are common responses to any life-threatening condition (Van Dyk, 2001). This includes HIV infection that is often associated with the death of the infected person; as well as other related losses. The findings of this study are in line with those reported by Vollmer and Valadez (1999). In their study amongst HIV-infected people in Kenya, where reactions like fear, anger, guilt, depression were also experienced. Only participants in Case II, reported depression symptoms such as, feeling low, loss of energy, lack of motivation, sleeplessness, hopelessness, crying and feeling useless. This can

be due to the fact that the infected family member in this case was at the AIDS phase which precedes death. Depression might also be associated to the multiple losses of family members due not only to AIDS, but also to the 1994 genocide. According to Elizabeth Kubler Ross's grieving stages (Kaplan & Sadock, 1998), depression is one of the reactions to death that can be experienced even in the face of impending death.

Fear was common in both cases. It was mainly associated with the fear of acquiring infection and possible stigma and discrimination. Fear of stigma and discrimination amongst HIV infected and affected people was also reported in Uganda (UNAIDS, 2001a) Burkina Faso (Issiaka et al., 2001); Kenya (Vollmer & Valadez, 2002); and the United Kingdom (Gaugh, 2003). Fear of acquiring infection, can be linked to the inaccurate information on HIV/AIDS. Despite accurate information on HIV transmission and prevention, participants in Case II experienced fear of acquiring the infection through casual contact. Similar findings were reported in Tanzania, Ethiopia and Zimbabwe (ICWR, 2002) which revealed that despite the accurate information, participants experience genuine fear of the casual transmission of HIV. This fear was thought to be linked to the strong fear of death that is triggered by the infection. In response to this fear, people may tend to adopt extraordinary risk-averse behaviour. Due to the high prevalence of the HIV infection, which seem not to confirm to the already known routes of acquiring the infection, people feel that there is another way of transmission that has not yet been discovered.

In Case II, fear was also associated with physical suffering of the infected family member. Pieters (1996), argued that fear of physical suffering is common amongst HIV infected and affected people. This is due to unpredictability of opportunistic infections that may occur. Lie

and Biswalo (1996), added that fear and other HIV-related emotional distress may contribute to the progress of their illness.

In Case I, fear was primarily linked to economic insecurity. In their study Barrett and Barrett (1994), found that fear was associated to the family economic decline. This leads to uncertainty about the future of the family.

In both cases, participants experienced anger, which is supported by the findings of that studies (Tallis, 1997; Vollmer & Valadez , 1999; Foster & Williamson, 2000; Majumdar, 2004) that reported anger amongst HIV infected and affected people. It was interesting note that the anger was directed towards different people who are thought to be responsible of what happened. In Case I, anger was directed towards the infected family member for misbehaving and also towards men for spreading the infection around. In Case II, the anger was directed towards to Sue's father, who was thought to have brought the infection in the family. They also blamed God who has allowed all these family deaths to occur. Smith (1995) asserted that blaming others helps to avoid a sense of responsibility to what has happened. This was found to have positive effects on the recovery from bereavement (Weinberg, 1994). However, Herman (2001), argued that self-blame gives the victim a sense of hope and control, as he/she may feel that if she is responsible for what happened he/she can change his/her problem behaviour, in order to prevent further consequences. The findings of this study supported this assumption; especially in Case I. Here, the infected family member reported that, though she misbehaved and got the infection, she decided to ask God for forgiveness and change her behaviour. It is worth noting that anger and blame of the infected family member can be linked to the problem of family interaction that was implicitly expressed in Case I.

The findings of this study support the results of the study conducted in India by Majumdar (2004) which revealed that participants experience anger towards their community around them for stigmatizing and discriminating HIV infected and affected people. This may be due to the real stigma and discrimination from the community, but also it may be a result of self-stigma. This may influence how others relate and interact with her, as well as how she interprets of these behaviours. Participants in Case II reported anger against the lack of family involvement in a health care plan for the infected family member. In a study conducted in Thailand (Jirapeat, 2001), it was revealed that the lack of involving clients in their health care plan resulted in non-compliance in using the available service.

The finding of shame in this study is in line with what ICRW (2002) reported in Tanzania. Shame was thought to be an integral component of HIV-related stigma and discrimination. Killian and Brakarsh (2004), mentioned that an internalized sense of one's own badness and unworthiness lead to the feelings of shame.

### **5.2.3 Coping strategies**

#### **5.2.3.1 Emotional focused coping strategies**

Emotional focused coping strategies included defence mechanisms, opportunity to talk, spiritual support, withdrawal behaviour, family relationships, disclosure, positive self-encouragement, distraction, alcohol abuse and going to night clubs.

Defence mechanisms were more common in Case I, as compared to Case II. In Case II, only denial was used prior to the HIV test. Uys and Middleton (2004), argue that defence

mechanisms help people to face the reality in a non-threatening way through the manoeuvre of deceiving themselves about the reality of their condition.

Denial, which was reported in both cases, is thought to be a normal reaction to threatening news; such as the death of a loved one, and a life-threatening condition, such as the diagnosis of an HIV infection (Kaplan & Sadock, 1998; Van Dyk, 2001). Melnyk et al. (2001), argue that denial is common, immediately after learning about HIV family member status. It may help to maintain emotional equilibrium for a short-time (Reeves, Merriam & Courtenay, 1999). It becomes problematic when it persists, and prevents infected and affected people from taking necessary action in order to deal with HIV related demands. In Case I, the infected family member tended to deny the fact that she would progress to the AIDS phase. This might imply a wish to die, without being a burden to the family because she is aware that presently, they are living from hand to mouth. However, this denial could prevent her and the family from taking the recommended action that would delay the progress of the infection. It would also inhibit the planning of her care demands, once she reached the AIDS stage. Studies conducted in the United States of America (Owens, 2003), and Uganda (UNAIDS, 2001a), revealed that denial of HIV and related demands, hindered emotional and material support that affected families would need to provide to their infected family member.

Suppression and humour are thought to be mature and healthy defence mechanisms that may have a positive effect on the emotional reaction to stressors (Uys & Middleton, 2004).

Findings of this study support the study of Reeves et al. (1999) in which participants reported positive effects of those mature defences; particularly humour. Rationalisation is classed amongst a neurotic defence mechanism that is mostly used by an adult under stress. In this study, it was assumed that it was meant to happen that HIV infected family member in Case I, would acquire the infection, and that this was a pre-destined cross that the family had to bear.



This rational approach to acquiring an HIV-infection, would undermine the way that one acquired infection. This would hence hinder prevention strategies that one could use, as well as eradicating control on acquiring and transmitting the virus. Reeves et al. (1999) consider the use of mature defences as a signal of health adaptation, rather than the use of neurotic ones.

Opportunities to talk to either a family member or a significant other, was seen as an effective coping strategy that was used in both cases. This included talking openly about HIV and related emotions or just talking to someone who not is aware of the infected family member's HIV status. In Case I, participants reported that sharing their concerns mostly with an outsider. In Case II, participants reported talking mainly amongst family members. These differences might be due to the relationship and interactions between members of each family. The positive effects of having someone to share one's HIV related concerns with, or just a normal talk were reported in a study conducted in Zimbabwe (Krabbendam, Kuijper, Wolffers and Drew, 1998). Gibson, Swartz and Sandenbergh (2002) state that everybody has in himself/herself an emotional container, which helps him/ to deal with his/her emotions. But, in some circumstances, such as when one experiences HIV related stressors, the container may be overflowing. In this case, it is helpful to have someone to talk to and in so doing pour out and ventilate these unbearable emotions. Parents of HIV infected children who participated in the study conducted by Lesar and Maldonado (1997) reported that talking to somebody helped them to cope with their emotions.

Disclosure was also mentioned as effective strategy used to deal with emotional reactions to HIV/AIDS. Participants in Case II revealed that keeping a secret around the infection increased their emotional reactions and affected the family interaction. Since the status of the

infected family member was disclosed to other family members and friends, it allowed participants to openly share their emotions, and provide mutual emotional support. Beverley et al. (2001) and UNAIDS (2001a) reported similar findings respectively in United States of America and Uganda.

Spiritual support was found to be a common coping strategy used in both cases. Participants reported that their faith in God helped them to deal with HIV related emotions. The infected family members in both families revealed that having faith in God helps them to face God without fear. Similar findings were also reported in other studies, such as the study conducted by Mahlangu (2001) amongst patients and nurses in South Africa; Woodard and Sowell (2001) amongst India women; UNAIDS (2001a) in Uganda. In this study, as well as the above mentioned studies, God was seen as source of power beyond human control; which one can rely on in everything. Actually, HIV seems to surpass human power and control, hence knowing and having access to God, who has power over the virus, can bring some relief. The other assumption could be that participants of this study were going through the bargaining phase of grieving; where healing was negotiated with God (Kaplan & Sadock, 1998). The infected family member in Case II, perceived death as a fulfilment of his/her life, and looked at her anticipated death as normal occurrence for everybody. It also could help her to deal with emotions associated with premature death as a young person, and help her view her impending death as timeous. In Case I, the infected family member reported that if she dies, she is going to a new world. Such a statement could imply the hope that one day the suffering she is now enduring will be over.

HIV-related knowledge helped participants to deal with their emotions. This was also found in Zimbabwean study (Krabbendam et al., 1998). Information is considered to be a useful

tool to challenge one's perspective (Egan, 1994). For example, knowing that other HIV infected people have survived for a long time, brought hope that the infected family member could live longer as well. In the Zimbabwean study by Krabbendam et al. (1998), participants reported that information on HIV/AIDS care helped them to perceive the infection as a manageable disease.

In Case II, positive self-encouragement and distraction had a positive effect on their emotions. These coping strategies were also reported in study conducted by Lewis and Brown, (2002). Positive self-encouragement is active strategy that helps in confronting the problem, and restructuring on a cognitive basis in respect of his/her stressor (Greenberger & Padesky, 1995). They argue that distraction helps the person to focus her/his attention away from emotional thoughts or situations, and thus relief. Avoidance was also considered as a passive strategy that can provide short-term emotional relief; but, this prevents the individual from getting used to or dealing with her emotional reactions (Greenberger & Padesky, 1995; Uys & Middleton, 2004).

Passive coping strategies such as withdrawal behaviour as seen by Uys and Middleton (2004) were also reported to be used by some participants. These coping strategies were also reported by affected families in Ugandan (UNAIDS, 2001a). In this case, instead of confronting the problem, one tends to move away from it as he/she may feel powerless and helpless. This behaviour was seen as an ineffective coping strategy by participants as it did not provide them with any emotional relief.

In a study conducted by Reeves et al. (1999) participants reported that alcohol using alcohol help them to deal with the emotions that were related to the situation they found themselves

in. This was also the case for the infected family member in Case II. In this study, these strategies were used as a form of distraction that would help them forget their concerns, and reduce related emotion. The participants did note that it did not offer the expected relief they were seeking.

#### **5.2.3.2 Problem focused strategies**

Coping strategies that deal with family stressors included treatment, family interaction to meet HIV related demands; socio-economic support from significant others and Mwana Ukundwa Association.

The availability and accessibility of effective treatment such as antiretroviral drugs and effective treatment for opportunistic diseases was one of the problem solving strategies. These findings are in line with results of the study of Lesar and Maldonado (1997) which reported that seeking medical information on infected family member's illness and care as well as providing her/him the best treatment, helped parents of HIV infected children to deal with their emotions. In this study, spiritual healing was also reported. Like the findings of the study conducted by Woodard and Sowell (2001), spiritual healing refers to healing directly from God; or indirectly; when God uses and/or gives wisdom to health-care providers to provide effective interventions. In this study the discovery of antiretroviral drugs was also seen as God's revelation to scientists

Family interaction in terms of care, involved working together in order to provide care for the infected family member such as, being with her, cooking special food, helping with hygiene and activities she could not do herself. Coping with economic demands consisted of finding a job in order to contribute and increase the family income, as well as doing household chores

that would require hiring another person, thus reducing the expenses. In their studies Lesar and Maldonado (1997), participants reported using family interaction to meet care demands. Nyblade and Field-Nguer (2001), Lie and Biswalo (1996), Foster and Williamson (2000), Knodel, Saengtienchai, Im-Em, and VanLandingham, (2001) and Owens (2003), found that in Botswana, Zambia, Tanzania, sub-Saharan African region, Thailand and the United States of America; family interaction effectively helped to deal with care and economic demands related to having a HIV infected person in the family. It should be noted that these studies, as well as the present study, family interaction involved even members from the extended family as case in Case I.

In Case II, family communication not only facilitated family interaction to meet care and economic demands, but also helped to deal with problematic behavioural reactions of the infected family member. According to Schoka et al. (2003) communication fosters a healthy relationship between family members. Uys and Middleton (2004) see such communication as an active dependence coping strategy; through which the person confronts another person so that they both seek the solution together. Withdrawal behaviour was reported when some family members coped with their problems by keeping them to themselves; so as to prevent additional demands to the family. It was reported that poor family communication is not rare in families that are affected by HIV (Schoka et al., 2003)

Significant others such as relatives, friends and institutions offer support to HIV-infected people such as Mwana Ukundwa Association; were seen as a support system for both families in order to deal with care, social and economic demands. This supported the findings for the study that was conducted in Rwanda (UNAIDS, 2001b), Uganda (UNAIDS, 2001a).

#### **5.2.4 Effects of family emotional reactions and coping strategies on the infected family members and the family as whole**

Family emotional reactions and coping strategies were found to have some effect on the infected family member as well as the family as whole. Both positive and negative effects of those reaction and coping strategies were reported.

##### **5.2.4.1 Effects of family emotional reactions**

Findings of this study revealed that the emotional reactions of each family member have considerable effect on the rest of the family. Participants on this study reported that family emotions depend mostly on the emotional state of the infected family member. The latter's emotions were also influenced by her physical health. Melnyk et al. (2001) reported that parents who see their chronically ill children in physical and/or emotional pain experience a wide range of overwhelming feelings. It was also found that a family's emotional responses in turn, affected the infected family members' emotions. It was reported that family emotions such as care, compassion, showing concern about her sufferings had positive effects on the infected family member. These findings are in line with the study of Owens (2003), where HIV-infected women reported the positive effects of perceiving their family members' emotions such as love, caring as well as a sincere attempt to show empathy and compassion.

It was interesting to find that some participants were not aware of the effects of their emotional reactions on the infected family member. Participants asserted that they sometimes tried to hide their emotions that are thought to have negative effect on the infected family member. Such behaviour can be considered as the desire to protect the infected family member. However, when the infected family member expected their emotional responses on her situation, hiding one's emotions was perceived as being indifferent. Often, in social interaction especially in African culture people tend to cover their emotions. People become

incongruent between what they feel and what they express. This may be due to human being early learning of expressing what will be accepted by others in order to seek acceptance from others (Brammer et al., 1993). It may also be due to the cultural background. In his study, Tsai (2003), found that some cultures value emotional control, whereas others value emotional expression. However, the findings for this study suggested that though emotional control would be valued in Rwanda, it may have negative effect and created a sense of emotional distance and not being caring towards the infected person. Other assumptions would be that participants were overwhelmed by their emotions and unable to express them.

Emotional reactions such as anger, unhappiness and hopelessness provoked negative effects on the family emotions; mainly because such emotions affected family communication. Uys and Middleton (2004), consider such reactions as a passive coping strategy which is mostly accompanied with a sense of guilt from family members. Instead of talking openly about their emotions, everybody would think that it is her/his fault.

#### **5.2.4.2 Effects of coping strategies**

Effective medical treatment and healing from God had a positive effect on HIV-infected family members and the rest of the family. These findings are in line with the findings of Lesar and Maldonado's study (1997), which reported that effective medical treatment and home care for infected people reduce emotional and care demands related to HIV/AIDS. Woodard and Sowell (2001) reported that participants in their study associated improvement of their health status with healing from God.

Social support that consisted of family interaction to meet HIV related demands as well as support from significant others and Mwana Ukundwa Association were seen as effective

copied strategies. These eliminated/reduced family stressors and related emotions. These findings are in line with results of the studies by Owens (2003), Serovich et al. (2001) and Jirapeat (2001) that revealed positive effect of social support to both infected family members and the family as whole such as reducing depression, anxiety and loneliness and increasing the feeling of belonging -which is of the utmost importance for the infected family member. Findings of this study supported results of Serovich et al.'s study (2001), which revealed that perceived support is more important than actual support. In this Case I despite the fact that everyone in family claimed to do his/her best to support the infected family member, the latter reported that her family was unsupportive. Consequently, the infected family member did not bother to seek help from other family members; she tended to withdraw from them especially in terms of communication. This may also explain her worries of what would happen to her children when she dies.

The perceived lack of family support may be associated with poor family relationships. This may be due to stigma and discrimination from others. It could also be due to the economic situation of the family. They do not really have the means to provide her with what she needs, as everyone in the family struggles to get their basic needs met. Furthermore, poor communication in this family may complicate the situation as one does not get the chance of expressing his/her concerns and trying to find a solution together as a family. Willo (2002), confirm that poor communication affects the family dynamic and can create family conflict.

It should be highlighted that this study found communication to be an effective strategy used to deal with social demands especially in terms of family interaction. In a Ugandan study (UNAIDS, 2001a) participants reported that open communication decreased negative emotional reactions and increased the care, feeling of belonging and love between family



members. This is supported by the findings from case II, where communication was used to sort out family interaction problems. This increased the family interaction for caring and understanding of the infected family member.

Solving or attempting to solve economic demands had a positive effect on the infected family member and the entire family. In their study, Wight et al. (2003), reported that family support reduced financial worries. According to conservative of resource theory (Freedy, Salain, Kilpatrick, Resnick, & Saubders 1994) the increase of family income can reduce the stress due to the economic insecurity being lessened. It may also be added when economic demands are met, as people can move on to other needs that are overshadowed by economic demands such as socio-psychological effects of HIV (Foster & Williamson, 2000).

### **5.3 Recommendations**

The findings of this study provide the useful information in terms of the mental health of an HIV affected family. The findings would have important implications not only to the nursing profession, but also to other domains, especially those who are involved in the care and support of HIV infected and affected people.

#### **5.3.1 Research**

The mental health of the HIV affected family was an important topic to be studied and much information has been found on this topic. However, it could not be thought that the present study has provided exhaustive information on the topic. More research on the topic would be helpful to fill in any gaps that still remain.

A quantitative study on the mental health of HIV affected persons that include a large, sample would give findings that could be generalized. It could be also interesting to conduct a study that includes family members that are not aware of the HIV status of the infected family member. It was reported in this study that they are also affected and can also have effect on the infected family member. In addition, families that do not get support from institutions such Mwana Ukundwa Association could provide additional information in respect of their mental health. Thus a study that draws a comparison between a supported and unsupported family could be interesting.

### **5.3.2 Practice**

The findings of this study revealed the effect of physical health, care and socio-economic aspects on the mental health of HIV affected families. These findings confirm the interrelatedness of all aspects of health. They also highlight and emphasise the importance of a holistic approach in caring for the infected family members. According to the findings of this study, it is important also to provide not only individual care; especially in terms of the mental health, but also emotional support for the entire family is vital. Such support is essential to increase a family's contribution in caring for their infected family member(s).

It was reported that some health care providers do not include the family in a health care plan for the infected family member. Health care professionals such as doctors, nurses as well as other health care providers, should note that the family is the primary health care provider; especially in terms of HIV/AIDS. Instead of leaving affected families out in caring for the infected person, the health-care providers should empower family members to participate in home-based care. This has been reported useful in HIV/AIDS care. Including affected families in health care is essential not only to facilitate a developing realistic care plan

according to the family means, but also to increase the infected family members' compliance to her treatment.

In view of the effect of coping strategies used by participants in this study, health care professionals should encourage and help the family to establish effective coping strategies; such as family interaction in caring, mutual emotional support, and meeting the economic demands as well as support from significant others and spiritual support. The role of communication in family interaction as they are dealing with their stressors and related emotions, was highlighted in this study. Affected families should be encouraged if necessary to use effective facilitated communication between members. In helping HIV affected families ineffective coping strategies such as alcohol abuse and withdrawal behaviour that affect family communication should be identified and dealt with.

### **5.3.3 Education**

The findings of this study highlighted the need for a holistic approach, where an emphasis is on bio-psycho-social model in understanding and caring for the infected and affected people. The spiritual aspect of the affected families should not be forgotten as it was found to have considerable impact in their life. Hence this approach should be emphasised in nursing training. In-service training for nurses would also improve the quality of care that nurses provide the infected and affected people. When it is necessary, training on case management that includes families in caring for their infected family member can be organized for nurses in practice as well as nursing students.

Psycho-education together with general education on HIV and AIDS should be used to provide family and community accurate and detailed information on HIV/AIDS. This

information should be provided to the individual, the family, as well as the community in an attempt to reduce the stigma and discrimination associated with HIV/AIDS. This will increase the participation of everyone in caring for infected and affected people.

#### **5.3.4 Institutions that support HIV/AIDS**

In supporting HIV infected people, it should be important to consider providing holistic support, or, at least know how to refer the infected and affected people for addition support. The support should include mental, social, economic, care and spiritual support. Infected family members should not be seen as being isolated from the rest of the family; hence the family should be considered in planning and dispensing any support.

It could be appropriate to review the support provided to HIV infected and affected people especially in developing countries as Rwanda and Uganda. Here, some poor families benefit from having an HIV-infected family member who qualifies for support they could not otherwise get. Care should be taken so that such support will not hinder the prevention of HIV/AIDS.

It could be useful to provide these families with support that will facilitate their empowerment. For example, instead of creating economic dependence to the association, families can be empowered to run their own income generating small project, which will increase family income and decrease reactions related to economic insecurity.

#### **5.4 Limitations of the study**

The main limitation of this qualitative study is the small sample size. The results of this study cannot be generalized as the sample can not be said to be representative. However, the findings of the study can be transferred to other populations that have similar characteristics with the study sample.

Though children are also part of their family and can be as affected as other family members, they were not included in this study because most of them did not know their HIV status or that of other affected family members. In this case ethics were considered for not provoking unwanted disclosure of the HIV status of the infected family.

Interviews were conducted in Rwandan and translated into English. Though care was taken to ensure faithful translation, this could not eliminate all possibility of loss of the quality of information as some Rwandan words do not have English equivalents.

#### **5.5 Conclusion**

In this study, the mental health of an HIV affected family was analyzed in terms of family's HIV related stressors, emotional reactions and coping strategies. It was found that family emotional reaction included shock, anger, sadness, hopelessness, and depression. These emotional reactions were seen as response to family stressors that can be put in four categories namely multiple losses, care, and social economic demands. Both emotional and problem focused strategies were used to deal with emotional reactions and stressors respectively.

Emotional reactions and coping strategies of the family were found to have an effect on both the infected family member as well as the family as a whole. Positive emotions that express

concern care and compassion had positive effects on the infected family member, and in turn had a positive influence on the entire family. Negative emotions such as anger, unhappiness, and hopelessness as well as hiding one's emotions had a negative effect on the family members.

The effective coping strategies used, consisted of defence mechanisms, opportunity to talk to someone, distraction, spiritual support, treatment, family interaction and socio-economic support for significant others, and institutions such as Mwana Ukundwa Association. These coping strategies were seen to have direct and indirect positive effects on both infected and affected family members. Negative effects were associated with ineffective coping strategies such as poor family communication due to withdrawal behaviour, alcohol abuse and going to night clubs.

There were differences between the findings in Case I and case II relating to the position of the infected family members in her family, family background in terms of economic status, family interaction, death of other family members and method of acquiring the infection.

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## **APPENDIXES**

### **Appendix A: Research approval from School of Nursing, Research ethics committee**



THE SOUTH AFRICAN CENTRE  
FOR EVIDENCE-BASED NURSING & MIDWIFERY



THE JOANNA BRIGGS INSTITUTE



UNIVERSITY OF  
KWAZULU-NATAL

## RESEARCH ETHICS COMMITTEE

Student: GLORIEUSE UNIZEYE

Research Title: AN ANALYSIS OF THE MENTAL HEALTH  
OF FAMILIES AFFECTED BY HIV/AIDS IN RWANDA

A. The proposal meets the professional code of ethics of the Researcher:

YES

NO

B. The proposal also meets the following ethical requirements:

	YES	NO
1. Provision has been made to obtain informed consent of the participants.	✓	
2. Potential psychological and physical risks have been considered and minimised.	✓	
3. Provision has been made to avoid undue intrusion with regard to participants and community.	✓	
4. Rights of participants will be safe-guarded in relation to:		
4.1 Measures for the protection of anonymity and the maintenance of confidentiality.	✓	
4.2 Access to research information and findings.	✓	
4.3 Termination of involvement without compromise.	✓	
4.4 Misleading promises regarding benefits of the research.	✓	

Signature of Student: [Signature] Date: 18th/06/04

Signature of Supervisor: [Signature] Date: 2004/06/18

Signature of Head of School: [Signature] Date: 22/06/2004

Signature of Chairperson of the Committee: [Signature] Date: 30/6/04  
(Professor F Frescura)

**School of Nursing, Howard College Campus**

Postal Address: Durban, 4041, South Africa

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Facsimile: +27 (0)31 260 1543

Email:

Website: [www.hc.ac.za](http://www.hc.ac.za)

## **Appendix B: Application letter to conduct the study**

University of KwaZulu -Natal  
Block 1 Room 17  
Anglo Cluster Residence  
Durban 4041  
27<sup>th</sup> May, 2004

Mwana Ukundwa Association  
B.P 1719  
Kigali  
Rwanda

Attention: Mrs Rose Gakwandi

Dear Madam,

**APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH STUDY AT  
YOUR INSTITUTION.**

I hereby apply for permission to conduct a research study at your institution. I am conducting this study for the fulfilment of the requirement for Master degree in Psychiatric Nursing and I need your assistance and cooperation. My research topic is:

**An analysis of the mental health of families affected by HIV/AIDS in Rwanda.**

The study of the mental health of families affected by HIV/AIDS is an important topic that might yield useful information for planning and implementing effective interventions for those families and in so doing empower them to provide their infected family members with effective care.

Anonymity and confidentiality will be maintained and all information will be held with utmost confidence.

I enclose the research proposal and clearance statement from the ethical committee of Nursing School, University of KwaZulu -Natal.

I hope my request will reach your most favourable consideration.

Yours faithfully,

G Uwizeye

Student. No 203513220

**Appendix C: Permission from Mwana Ukundwa Association**





# ASSOCIATION MWANA UKUNDWA (A.M.U) A.S.B.L

B.P 1719 Kigali, Rwanda Tél. 514648 Mobile : 08305900 E-mail : amu@rwanda1.com

Glorieuse UWIZEYE  
University of KwaZulu Natal  
Block 1 Room 17  
Anglo Cluster residence  
Durban  
4041

28<sup>th</sup> June, 2004

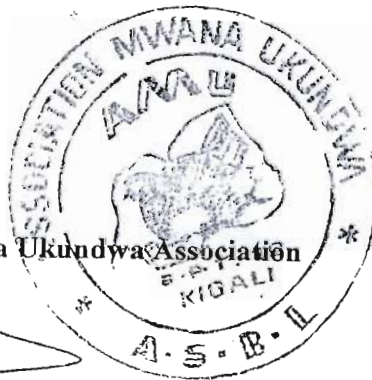
Dear Miss Uwizeye

You have the Mwana Ukundwa Association permission to undertake a research project in our HIV/AIDS project.

Yours faithfully

Mrs Rose Gakwandi

Co-ordinator of Mwana Ukundwa Association



## **Appendix D: Consent to participate**

## **Consent to participate**

University of KwaZulu -Natal

Block 1 Room 17

Anglo Cluster residence

Durban 4041

18<sup>th</sup> June, 2004

Dear Sir/Madam,

I am currently registered with University of KwaZulu- Natal (Durban) for Masters Degree in Mental Health Nursing. I am conducting a study on:

### **An analysis of the mental health of families affected by HIV/AIDS in Rwanda**

The study of the mental health of families affected by HIV/AIDS is an important topic that might yield useful information for planning and implementing effective interventions for those families and in so doing empower, them to provide their infected members with effective care. Hence your participation will be an appreciable contribution to achieve that aim of the study. Please note that a tape recorder will be used during the interview and the interview transcript will be translated into English by the researcher and another expert translator. The confidentiality will be maintained at all times. Participation in the interview is voluntary and you are free to terminate your participation at any time.

You are requested to sign written form of consent if you are interested to be part of this study. Your participation in this study is highly appreciated.

Yours faithfully,

G. Uwizeye

St No: 203513220

## **Participant sign consent**

I .....agree to participate in the research of **an analysis of the mental health of families affected by HIV/AIDS in Rwanda**. I promise to answer all the questions as accurately as possible. I also understand that the information I give will be kept in confidence and be only used for the research purposes. I also understand that I can stop participating at any moment.

Thank you

The participant

Signature.....

**Appendix E: Interview Schedule**

## Interview schedule

Objectives	Questions
<p>1. To describe the mental health status of families affected by HIV/AIDS.</p> <p>1.1 To explore the emotional reactions experienced by the family members.</p> <p>1.2 To identify HIV/AIDS related stressors of family affected</p> <p>1.3 To explore and describe the coping strategies adopted by the family members.</p>	<p>1.1.1 How did you react when you heard that your family member is HIV positive?</p> <p><b>Prompts:</b></p> <p>How did you react initially?</p> <p>What are your current emotional reactions?</p>
	<p>1.2.1 What happen when you get those emotions?</p>
	<p>1.3.1 How did you deal with those emotions?</p> <p>1.3.2 What are the changes related to HIV/AIDS that have happened to your family?</p> <p>1.3.3 What do you do to cope with those changes?</p>
<p>2. To describe how these reactions and strategies affect the HIV positive family member and the whole family unit.</p>	<p>2.1 What is the impact of your emotional reactions and coping strategies has to the infected family member and whole family unit?</p> <p><b>Prompts</b></p> <p>What changes have those reactions and strategies made to the family relationship with each other/or the HIV infected member?</p>

## **Appendix F: Case Protocol**

# **Case protocol**

## **1. Physical address**

1.1: Area

1.2 District

1.3 Province

## **2. Home environment**

2.1 Type of house

2.1 Number of family members

2.2 Type of family

2.2.1. Nuclear family

2.2.2. Extended family

2.2.3 Child headed family

2.2.4 Other (specify)

2.3 Position the infected family

## **3. Source of information**

3.1 Individual

3.2. Family as group focus

## **4. Data collection strategies**

4.1 Semi-structured individual and focus group interview.



## **5. Data to be collected**

### **5.1. The mental health status of HIV affected family**

#### **5.1.1. Emotional reaction of family members**

#### **5.1.2 Family HIV related stressors.**

#### **5.1.3 Coping strategies of the family**

### **5.2. Effect of those emotional reactions and coping strategies to the infected member and the family as whole.**

## **6. Questions to be asked**

### **6.1 How did you react when you heard that your family member is HIV positive?**

### **6.2 What does it trigger those emotions?**

### **6.3 How did you deal with those emotions?**

### **6.4 What are the changes related to HIV/AIDS that have happened to your family?**

### **6.5 What do you do to cope with those changes?**

### **6.6 What is the impact of your emotional reactions and coping strategies has to the infected family member and whole family unit?**

## **Appendix F: Case Protocol**

# **Case protocol**

## **1. Physical address**

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5.1. The mental health status of HIV affected family

5.1.1. Emotional reaction of family members

5.1.2 Family HIV related stressors.

5.1.3 Coping strategies of the family

5.2. Effect of those emotional reactions and coping strategies to the infected member and the family as whole.

## **6. Questions to be asked**

6.1 How did you react when you heard that your family member is HIV positive?

6.2 What does it trigger those emotions?

6.3 How did you deal with those emotions?

6.4 What are the changes related to HIV/AIDS that have happened to your family?

6.5 What do you do to cope with those changes?

6.6 What is the impact of your emotional reactions and coping strategies has to the infected family member and whole family unit?


## **Appendix G: Certificate of editing**

**To whom it may concern**

This is to certify that I, Erika Brysiewicz have edited the Masters dissertation that was researched and written by Glorieuse Uwizeye: Student no: 203513220.

The title of the dissertation is:

**An analysis of the mental health of families affected by HIV/AIDS in Rwanda.**

  
\_\_\_\_\_  
Erika Brysiewicz  
B.A. (History, Legal Studies); A.U.D.I.S.  
P.G.C. (English, History)