

**TITLE : AMBIGUOUS LOSS AND GRIEF REACTIONS AMONG ADOLESCENTS WITH PARENT(S)
DIAGNOSED WITHY HIV/AIDS. IDENTIFYING MODERATING FAMILY QUALITIES/
RESILIENCE FOR INTERVENTION.**

BY

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A THESIS

Submitted in fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

IN CLINICAL PSYCHOLOGY

In the

FACULTY OF HUMANITIES

(School of Social Sciences)

At the

UNIVERSITY OF LIMPOPO

SUPERVISOR: Prof T-A.B Mashego

2019

DEDICATION

To my husband and our three sons: Brian, Tlabego, and Selaelo, who have always been the source of my support and inspiration; to my mother Mapula Elizabeth Nkwana and my mother-in-law, Molatelo Sophia Sathekge, who always took pride in me; and in loving memory of my uncle, Mahakantshe Ike Kgatla.

DECLARATION

I, **SATHEKGE MAITE KATE**, declare that **AMBIGUOUS LOSS AND GRIEF REACTIONS AMONG ADOLESCENTS WITH PARENT(S) DIAGNOSED WITH HIV/AIDS: IDENTIFYING MODERATING FAMILY QUALITIES/ RESILIENCE FOR INTERVENTION** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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Full names

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Date

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Student number

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Signature

ACKNOWLEDGEMENTS

I would like to acknowledge the following people without whom this work may not have been completed:

My supervisor, Professor T-A.B Mashego for her support and advice. Her comments and feedback have been valuable and very much appreciated. Her commitment to my growth made me develop immensely as a scholar and I promise to continue on this path for many years to come.

To all my family members who directly and indirectly supported me, and the support encouragement and constant motivation that I got from my husband, Dr Morokolo Silas Sathekge. However, at times you behaved like my father. I didn't like it, but it was rewarding. I also acknowledge my husband for translating the long questionnaires into Sepedi and back into English.

To my sons who have always been the source of my strength, in particular Brian. Knowing that you were out there working in the cold weather when everyone else was sleeping, kept my light on. I believe your labour is not in vain.

My parents, whom I knew take pride in my achievements.

My colleagues, in particular, Mr Mokoti, who assisted in interviews and ensuring that psychological services are offered to those in need, and Ms Mamoloko Rachidi for her input and encouragement.

The research assistants who assisted with the collection of data.

The department of health staff members who provided me with the participants and the venue for the interviews.

All the participants, parents and children, who were willing to share their stories of pain with me.

The Sekomana family, in particular Motlatjo and Madidimalo, for inspiring my interest in grief and family resilience.

To God Almighty who provided me with good health, wisdom, strength and all the people who supported me during my period of study

ABSTRACT

The aim of the study was to determine the experience of ambiguous loss and grief reactions in adolescents affected by parental diagnosis of HIV/AIDS, and the identification of potential resilience factors that moderate the grieving symptoms.

A convenient sample of 159 adolescents ninety-five (95) from families with a parental diagnosis of HIV/AIDS and a control group of sixty-four (64) adolescents whose parent(s) were diagnosed with cancer, participated in the study. The age of the participants from both families fell in the following ranges: 11-14 (n=45), 14-17 (n=65), 17-18 (n=45), 18 and above (n=2). Eighty-nine (89) were females whereas seventy (70) were males.

A triangulation method of data collection was used wherein a biographical questionnaire designed by the researcher, a TRIG questionnaire to assess the level of grief in the participants and resilience scales were used in the quantitative phase. The family resilience scales included Family attachment and changeability Index 8 (FACI-8), Family Crisis Orientated Personal Evaluation Scale (F-COPES), Family Hardiness Index (FHI), and Relative and Friend Support Index (RFS). The Pearson correlation was used to identify the significance of potential resilience factors present in the affected families. Regression analysis was used to determine the predictability of variables to show moderating effect of resilience factors on the impact of experience of an ailing member of the family.

Interviews were held with the adolescents in the qualitative phase using semi-structured interview schedule. The questions elicited qualitative responses on the participants' feelings towards the illness of the parents, the role they are playing and feelings towards the role, experience of feelings of loss, disclosure and the family qualities perceived to be helping them adapt to the stress of having a sick parent.

The results showed that the two groups experienced ambiguous loss in the form of boundary ambiguity marked by enforced role changes following indisposed parent due to ill-health. Both groups of adolescents experienced forms of grief during the ailment of the parent(s). HIV/AIDS affected group experienced delayed grief whilst the control group of cancer affected individuals experienced acute and prolonged grief. Parental disclosure following diagnosis was higher among cancer affected

families (75%) than those affected by HIV/AIDS (55%). There was, however, no significant difference between disclosure of disease status and the experience of grief, $p=0.0120$. Potential resilience factors in both families were F-COPES, FHI, and FACI-8. These factors were also found to have a moderating effect on the experience of grief in the HIV/AIDS affected families, but showed the opposite effect on the experience of grief in the cancer affected families. This shows the uniqueness of the study in the way the HIV/AIDS and Cancer affected families responded differently to the moderation of the resilience factors. The difference in the impact is in line with the shift in the status of HIV/AIDS from being a terminal condition to being manageable and considered chronic in contrast to cancer. The shift was seen occurring also in this study where previously high grief was associated with HIV/AIDS as its diagnosis was regarded as a death sentence. There was high stigma associated with HIV/AIDS diagnosis until recently when it was found to be controllable and also positively impacting on the life expectancy in South Africa that increased from 53 to 64 years post utilization of ARV's.

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CHAPTER 1

ORIENTATION OF THE STUDY

1.1 INTRODUCTION

Africa has the fastest growing HIV/AIDS pandemic in sub-Saharan Africa with an average prevalence rate of 10.8 percent in the general population. The HIV/AIDS epidemic has killed more than 2.4 million people in sub-Saharan Africa in 2005, while an estimated 3.2 million more people acquired HIV/AIDS (Richter, Foster & Sherr, 2006). According to UNAIDS (2016), adolescents and young women are at a higher risk for new HIV infections (20%) than among adults (11%) globally in 2015. The imbalance is more pronounced in sub-Saharan Africa, with 25% of new HIV infections in adolescents and young women as opposed to 17% in adults in 2015.

South Africa is one of the countries in Africa to be affected by the HIV epidemic with an estimated 5 million people infected by the beginning of 2003 (Evian, 2003). Statistics South Africa estimated a total of 6.19 million people were living with HIV in 2015. Of this group, 16.6% are adults aged 15-19 years (UNAIDS, 2016). The ARV programme maintains the prevalence of HIV as people living with HIV live longer. An increased prevalence rate of 18.0% in females and 4% in males has been estimated among adults in South Africa between the years 2004-2007 (UNICEF, 2007). This increase leads to an increased number of children and adolescents affected with HIV/AIDS in the world. According to UNICEF (2015), by the end of 2011 about 17, 3 million children under the age of 18 years had lost one or both parents to HIV/AIDS, and a million more face the possibility of losing their parents to HIV/AIDS.

Most HIV/AIDS sufferers are adults who are taken care of by their own children and sometimes by parents, or grandparents. Such responsibility can leave caregivers, especially if they are still young, in a state of confusion due to prolonged uncertainty around the disease progression. Unlike the traditional final death (i.e. death due to other causes), the perceived loss whilst the family member is alive and still with the family can often be very difficult for affected individuals due to the uncertainty. Studies conducted by Cluver, Orkin, Gardner & Boysen (2012) showed that losing a parent to HIV or living with an

HIV/AIDS infected parent is a significant risk factor to child and adolescent development, due to what caregivers can perceive as having a potential to lead to a dreaded possible outcome.

Boss (2006) refers to such perceived loss associated with a dreaded and a life threatening disease progression as a situation that can be described as an experience of ambiguous loss. She defines 'ambiguous loss' as a situation where a sick family member is being physically present during the ailing period, but psychologically absent due to the reduction in communication and/ or interaction with those around him or her and vice versa. Lack of clarity of what is happening and should be expected, and having no information about the prognosis and also just being here and not really being present, creates immense pressure on the family that becomes perpetually engaged in trying to make sense of their situation around the ailing family member.

The elements described by Boss (2006) emerge in situations around patient care and especially at the time of the diagnosis of conditions that may be chronic, terminal and which may have a poor prognosis. Conditions that bring immense life changes to the loved ones, and conditions that physically remove the loved one from the family, where the person is not available in the family physically, but then continues to be in the minds of the family members. Some conditions are such that the sick member is present physically, but cannot engage anymore with the family. The conditions suffered by the ailing family members in this category include amongst others, brain injury, dementia, cancer and HIV/AIDS. Pauline Boss describes the experiences of families with such sick family members as being exposed to perpetual ambiguity around the sick members' condition, resulting from looming 'loss' and the unfinished-ness of the removal of the family member from his or her home caused by the sickness. For the HIV/AIDS infected, affected family members are in a state of perpetually trying to make sense of what in their eyes is a progressive deterioration of a sick family member, and this gets worse if there has not been any disclosure, especially for the child caregivers (Boss, 2002, 2006; Abramson, 1990).

The experience of ambiguous loss is particularly traumatic because of the inability to resolve the situation. Clearly, the on-going nature of ambiguous loss challenges families in these situations and, in contrast to death, families experience no closure with no resolution.

Mourning for these patients starts to take place with the person still physically present exacerbated by being psychologically absent.

Some studies, although few, suggest that some children affected by HIV/AIDS do not report clinically significant or elevated levels of mental health problems over time (Chi, Li, Barnett, Zhao & Zhao, 2013; Pelton & Forehand, 2005). This is due to the resilience that some children show in the face of adverse life events. Literature has in the past, documented the significance of resilience in moderating the child's response to a wide range of adversities such as poverty, parental divorce, parental mental illness or physical illness, and disastrous life events (Fraser & Pakenham, 2008; Gewirtz & Edleson, 2007). There is currently an emerging interest in resilience among children affected by the parental HIV status (Betancourt, Meyers-Ohki, Charrow & Hansen, 2013; Islam, Munichiello & Scott, 2014).

Although resilience is recognized as inversely proportional to the experience of negative emotions during adversity in most children, there is little documentation on its moderating effect. This research aims to identify family qualities that have a moderating effect on families affected by HIV/AIDS and how they differ with those affected by cancer.

1.2 BACKGROUND TO THE PROBLEM

HIV prevalence among women aged between 30 and 34 remains the highest, increasing from 41.5% in 2009 to 42.2% in 2011. Among the 35 to 39 year olds, the prevalence rate increased from 35.4% in 2009 and 39.4% in 2011. Although a decrease in the prevalence rate was noted in some provinces, Limpopo is one of the provinces that showed an increase from 21.4% to 22.1% (Khumalo, 2012).

Most affected adults take care of their adolescent children, and in some cases children often assume care-giving roles, often without needed basic necessities such as disinfectants, gloves, bedding etc. (UNICEF, 2012). Most children find this very foreign to them as they have never taken care of a seriously ill person before, nor have they seen someone die. In the case of HIV/AIDS affected children together with the parent/s have to live with the knowledge that ultimately the ill parent may die. In the ARV clinics, children often accompany parents for treatment, and in most cases, as the only source of support

for the sick parent. This is in contrast to the African tradition where elders (siblings or parents to the sick, especially females) often play the caregiver role. The burden of such caregiver roles by children is heightened by the fact that most HIV/AIDS infected patients prefer not to disclose their status to young children for fear of rejection and of being judged by the older generations (UNAIDS, 2008).

Children who are orphaned as a result of HIV/AIDS start to mourn long before the actual death of a sick parent and thus experience intense trauma of having to deal with impending death of a parent. This makes orphanhood become a long process which in a normal situation should only start when the parent dies.

The current research thus aims at determining experiences of the impact of such impending loss on HIV/AIDS affected children, the extent of grief related symptoms experienced and if the qualities of their family background have any influence on their resilience and how such resilience could buffer existing grief symptoms

1.3 STATEMENT OF THE PROBLEM

The needs of children living in households with sick adults and/or sick siblings are seldom recognised or adequately addressed in policy and programmes. With over 5 million HIV positive South Africans, an estimated 500 000 children currently have a mother who is terminally or chronically ill with AIDS (Brewer & Sparkes, 2010).

Youth who live with a parent suffering from AIDS, often have to deal with stressors and potential exposure to greater risk for HIV infection and other negative outcomes. Distressed youth may use drugs as a means of alleviating unpleasant feelings and to cope with frustration or anticipated failure (Ritchter & Mofeson, 2014). Most children take care of their terminally ill parents, and frustrations and guilt feelings have been reported during the clinical work performed by children who were faced with having to bathe their own parents, especially if the caregivers were boys. For them such practice is traditionally a taboo, and thus difficult for them to change the traditional values during this period.

According to Boss (2006), the experience of 'ambiguous loss' comes when people, especially children cannot bring their perceptions of what they are supposed to do in line with personal familial and community expectations. Their identity remains in limbo and they feel increasingly confused and ambivalent by not knowing who they are or what they are expected to do in relation to a physically or psychologically 'absent' family member due to illness. Although the task is more traumatic when there is 'ambiguous loss', the maintenance of health depends on the resiliency to be able to tolerate the sick person's continually changing identity that is not quite clear and may never be. There is thus recently an increased interest in resilience among children affected by parental HIV/AIDS (Betancourt, Meyers-Ohki, Charrow & Hansen, 2013).

This research explored ambiguous loss and the grief reactions among adolescents whose parents were diagnosed with HIV/AIDS. It further identified the family qualities and resilience factors that buffer grief reactions, to assist health care providers in tailoring their intervention towards strengthening the families.

1.4 AIM OF THE STUDY

The aim of the study was to determine the experience of ambiguous loss and grief reactions in adolescents affected by parental diagnosis of HIV/AIDS and identification of potential family qualities and resilience factors that moderate grieving symptoms.

1.5 OBJECTIVES OF THE STUDY

The objectives of the study were:

- To establish if adolescents' experiences of ambiguous loss in families that have HIV/AIDS diagnosed parent(s) will differ from those in families that have the parent(s) diagnosed with other conditions.
- To determine if HIV/AIDS affected adolescents experience forms of grief-related symptoms during their parents' illness and if that differs from those affected by other conditions.

- To find out if there are any demographic differences in the adolescents' experience of ambiguous loss and grief related symptoms.
- To establish if parental disclosure of the status of HIV/AIDS has any effect on the affected adolescents' development of ambiguous loss and grief related symptoms.
- To determine if family qualities and resilience factors will have a moderating effect on the experiences of ambiguous loss and grief reactions by affected adolescents.
- To show if family qualities and resilience factors associated with the moderation of 'ambiguous loss' and grief related symptoms among affected adolescents in HIV/AIDS affected families are unique and differ from those factors that sustain families affected by other conditions.

1.6 HYPOTHESES

The following hypotheses were proposed:

- The experiences in families that have HIV/AIDS diagnosed parent(s) will differ from those in families that have parent(s) diagnosed with other conditions.
- HIV/AIDS affected adolescents experience forms of grief related symptoms during their parents' illness that will differ from those affected by other conditions.
- Affected adolescents experience ambiguous loss and grief reactions whilst caring for the ailing parent and this differs according to the demographic factors.
- Disclosure/nondisclosure of parental HIV/AIDS status influences the development of ambiguous loss and grief related symptoms in the affected adolescents.
- Family qualities and resilience factors will have a moderating effect on the experiences of ambiguous loss and grief reactions by affected adolescents.
- Family qualities and resilience factors associated with the moderation of ambiguous loss and grief related symptoms among affected adolescents in

HIV affected families are unique and differ from those factors that sustain families affected by other conditions.

1.7 SCOPE OF THE STUDY

The study will cover children and adolescents between the ages 11 and 18 years, whose parents or caregivers are chronically ill due to HIV/AIDS or cancer, from the areas in the Capricorn District, Limpopo. Assistance in identifying the sample will be sought from the HIV/AIDS support groups, area social workers, ARV clinics, and hospital oncology wards/clinics. Those patients in the oncology ward but not residing in the district will be excluded from the sample. Participants will be selected irrespective of their religious denomination, socio-economic status, level of education, sex, level of psychological distress, level of social support, and disclosure.

1.8 SIGNIFICANCE OF THE STUDY

Various models for treatment are available for caregivers with scarcity of treatment models available to health professionals to treat bereaved young people. This study will provide important data on the adolescents' experiences and potentially modifiable resilient resources, for developing and testing family strengthening interventions for HIV/AIDS affected children and their families.

1.9 CONCLUSION

This chapter outlined the background to the experience of ambiguous loss and grief reactions in adolescents with a parental diagnosis of HIV/AIDS as well as the family qualities that moderate the experiences of the grief symptoms. It further presented the statement of the problem, the aim, objectives and hypotheses of the study, the scope as well as the significance of the study.

CHAPTER 2

THEORETICAL FRAMEWORK

2.1 INTRODUCTION

This chapter will discuss the theoretical models for grief and ambiguous loss, operational definition of terms as well as a discussion of the theories of family resilience that could help to moderate grief and ambiguous loss. The theories for grief and ambiguous loss will be discussed in the context of attachment theory and systems theory. The Resilience model of family stress, adjustment, and adaptation will be discussed as a theoretical model.

2.2 OPERATIONAL DEFINITION OF CONCEPTS

- **Ambiguous loss**

This concept “ambiguous loss” as coined by Boss (2006) refers to the sick family member who, due to a debilitating ailment, is sometimes experienced as if he or she is no longer with the family. This happens in situations where ailing members could be so sick that they are no longer able to do their normal work and are seen as being psychologically absent, or sometimes not being able to connect with the family at an emotional level, or due to dementia as a result of the condition suffered. The experience of ambiguity due to the physical presence or absence of the family member can be experienced as anticipatory loss. Such grief is defined as the distress and related emotions, cognitions, and behaviours that occur before an expected loss.

The present study used ambiguous loss as a situation whereby caregivers, due to the illness of the loved ones, are not able to engage in some of the normal work they are supposed to do.

- **Grief Related Symptoms**

Grief is defined as a system of feelings, thoughts and behaviours that are triggered when a person is faced with loss or threat of loss (Jeffreys, 2005; Melhem & Brent, 2011; Valentine, 2008). It is often described by those that have gone through it as a heaviness that is not easily lifted. According to Rando (2000) and Carpenito-Moyet (2009), grief symptoms include yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings and a variety of physical symptoms unique to the individual. The grief related symptoms in this study will thus refer to those emotional, positive and physical symptoms that the participants present with following the illness of the parent. An acute grief response is defined as a common response that occurs before, during, and/ or immediately after the death of a loved one. For the purposes of this study, an acute grief response will occur immediately after the parent falls sick.

- **Adolescence**

Adolescence is defined as the period of time from the onset of puberty until an individual achieves economic independence. An adolescent is thus defined as a juvenile between the onset of puberty and maturity. For the purposes of this research, adolescents are defined as youth aged between 11 and 18 years of age.

- **Resilience**

Boss (2006) defines resilience (from the stress perspective) as the ability to stretch (like elastic) or flex (like a suspension bridge) in response to the pressure and strains of life. This includes the normative stress from everyday hassles as well as the expected family transitions of entrances and exits (birth and death) across the lifespan.

It is further defined as the skills, abilities, knowledge and insight that accumulate over time as people struggle to surmount adversity and meet challenges. It is an ongoing and developing fund of energy and skill that can be used in current struggles (Truffino, 2010).

For this study resilience means the ability to bounce back following adversity as it is formally defined.

- **Families**

Families have been described as “the ecological system that nourishes the individual” and as the primary “social service agency in meeting the social, educational and healthcare needs” of members (VanBreda, 2001).

In this study, family will refer to the nuclear family of parents and children and extended family of parents’ siblings and parents.

- **Family resilience**

Family resilience refers to the characteristics, dimensions, and properties of families, which help families to be resistant to disruption in the face of change, and adaptive in the face of a crisis situation (Truffino, 2010). It can also be defined as the positive behavioural patterns and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family’s ability to recover by maintaining its integrity as a unit while ensuring, and where necessary restoring, the well-being of family members and the family unit as a whole (McCubbin & McCubbin, 1996; Ungar, 2011). For this study the same definition will be used.

2.3 THEORETICAL MODEL

Resilience Model of Family Stress, Adjustment and Adaptation

The current study was designed within the resilience model of family stress, adjustment, and adaptation based on ABCX and double ABCX models (McCubbin, Thompson & McCubbin, 1996; McCubbin & Thompson, 1991).

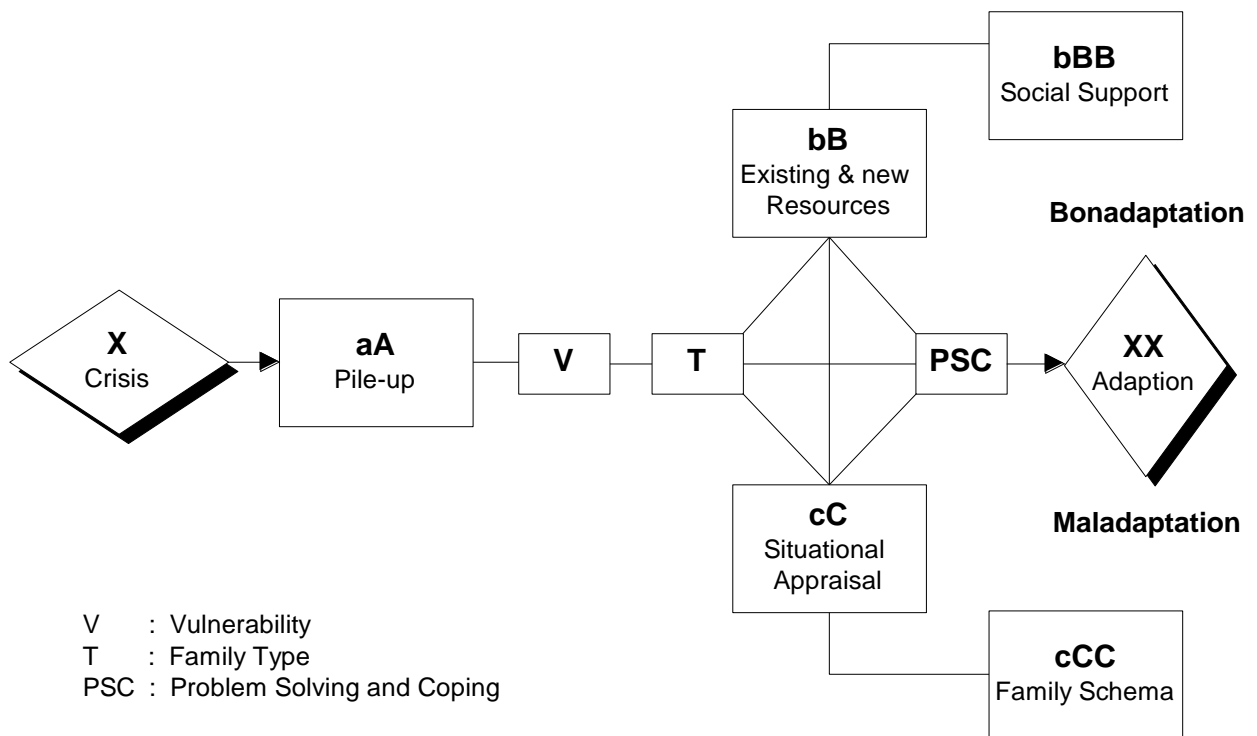


Figure 1: The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, Thompson & McCubbin, 1996; McCubbin & Thompson, 1991)

2.3.1 Conceptual framework of the ABCX model

The ABCX model is the original family stress model developed by Reuben Hill in 1949, and it is used to explain the “crisis- proneness and freedom from crisis among the families” (Friedman, 1998; McCubbin, Thompson, Thompson & McCubbin, 1993). Hill (1958) labeled the components as A (the crisis precipitating/stressor event), B (the family crisis- meeting resources), C (The definition the family makes of the event), and X (the crisis) (McCubbin *et al.*, 1993; McCubbin & McCubbin, 1996; VanBreda, 2001; Boss, 2006).

2.3.1.1 Factor A: The crisis precipitating event/stressor

The crisis precipitating event and stressor means a situation a family did not anticipate which produces or has the potential to produce a change in the family’s social system. Examples of areas of family that could be affected include the goals, roles, pattern of interaction, boundaries, or values. (Hill, 1958; Mikhail, 1981). The stressor affects families differently based on the hardships that accompany them. Hill (1958) defined hardships as

complications of a stressor that demand resources from the family. Hardships include among others, a family's need for money or to rearrange the roles to meet the medical needs and care for the ill member.

It thus means both the stress and its hardships put demands on the family system which must be managed.

2.3.1.2 Factor B: The family crisis meeting resources

Hill (1958) theorised that the family crisis meeting resources are the factors in the family that by their presence, keep the family from a crisis or, by their absence, urge the family into a crisis. Social relationships are further distinguished as being within the family variables e.g. attachment, positive family bonds, effective communication, as well as across family variables i.e. social isolation vs. informal and formal social networks (McCubbin *et al.*, 1993; VanBreda, 2001; Boss, 1999, 2002, 2006).

2.3.1.3 Factor C: Family definition of the stressor

The subjective meaning the family gives to the stressor determines whether the family will experience a crisis or not. The family that defines the stressor events and accompanying hardships as crisis-producing rather than challenges becomes more prone to crises (Hill, 1958). Accordingly, a crisis precipitating event, family resources and the family's definition of the event interact to produce a crisis.

2.3.1.4 Factor X: Family Crisis

A crisis is defined as a sharp or decisive change for which old or ongoing roles are inadequate (Hill, 1958). Blanchard (1997) further defines it as a situation in which a change brought about disruption in the family system. According to McCubbin and Patterson (1983), stress may never reach crisis proportion if the family is able to use existing resources and define the situation so as to resist systemic change and maintain family stability. Families with members diagnosed with serious illness e.g. HIV/AIDS might experience a sharp change when the parents, due to their ill health are not able to care for

their children adequately. In most cases children assume parental roles, thus causing disruption in the family system.

2.3.1.5 Application of ABCX model to ambiguous loss

In applying the ABCX model to 'ambiguous loss', Boss and colleagues (Boss, 2006, Boss & Carnes, 2012) theorised that an 'ambiguous loss' occurs when a level of uncertainty is present in a perceived loss by an individual. Here, 'ambiguous loss' is viewed as being the A factor or the event and/or situation that may lead to distress. Moreover, the ambiguity that is derived from not knowing whether a perceived loss is absolute, results in a delayed coping process for the individual experiencing the loss. Due to this delay, the individual develops distress and can become immobilised in a state of uncertainty, contemplating whether he or she should continue to grieve or move on with their lives. Feelings of hopelessness, confusion, guilt and ambivalence are common responses to this form of loss. Individuals may also present with symptoms resembling those of complicated grief, or depression, anxiety, and ambivalence. These feelings can impact a person's relationships with others, ability to process emotions and/or complete tasks and confusion regarding familial roles.

In some cases, the individual may finally come to the decision to move on, but is unable to identify ways in which he or she should move forward. This form of loss differs from the more traditional form of absolute loss (i.e. death) in that the lack of finality which surrounds the 'ambiguous loss' can make it more difficult for the individual to cope effectively.

In addition, the lack of ritualistic acknowledgement of a loss makes the grieving process for an 'ambiguous loss' more difficult to deal with, as rituals help towards closure.

2.3.2 Conceptual framework of the Double ABCX model

Figure 2 below shows the double ABCX model adapted from McCubbin and Patterson (1983)

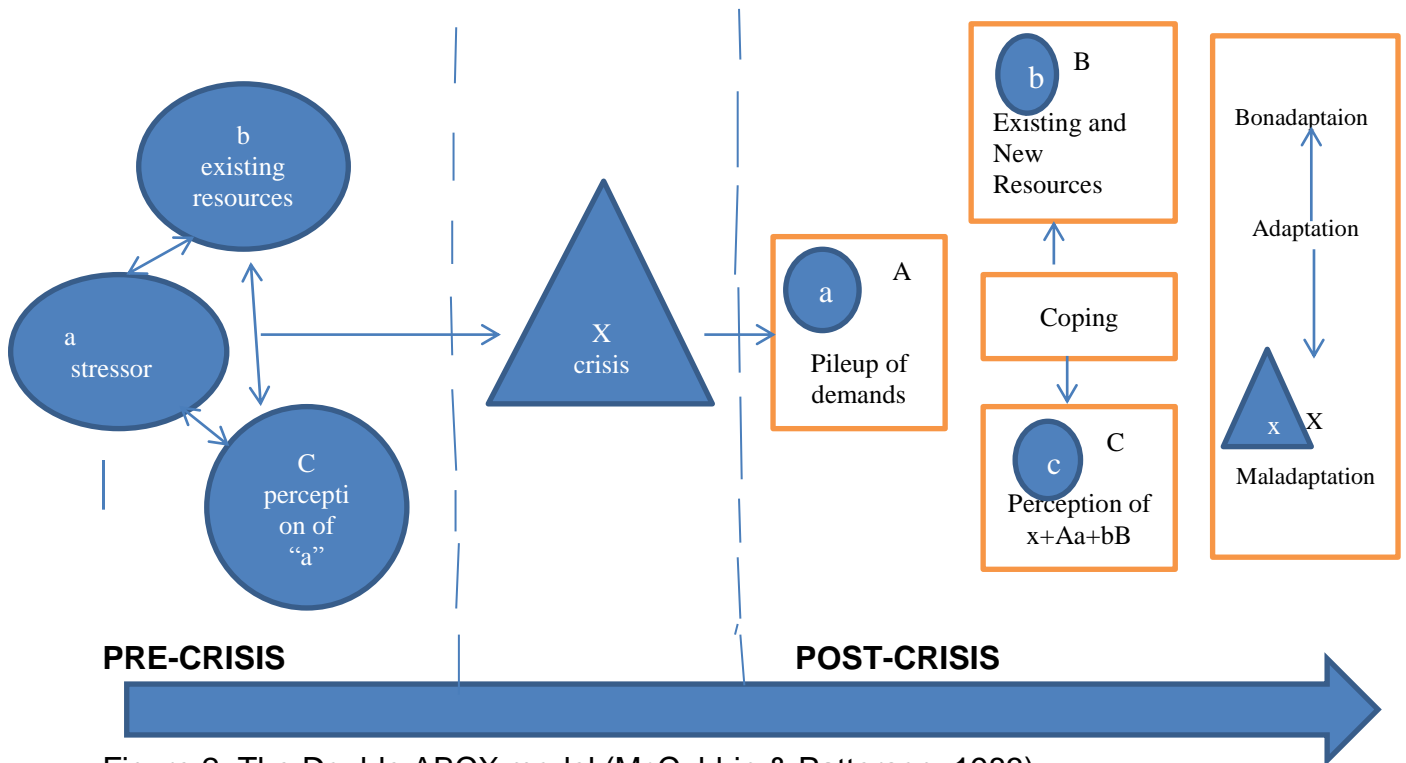


Figure 2: The Double ABCX model (McCubbin & Patterson, 1983)

Hill's (1958) ABCX model was used initially to guide a longitudinal study of families with a father/husband unaccounted for in the Vietnam war. The study revealed additional factors influencing the course of family adaptation over time. McCubbin and Patterson (1983) used the results to expand on Hill's original model of family stress by adding post crisis variables to explain and predict how families recover from crisis and why some are better able to adapt than others, Resiliency Model of Stress, Adjustment, and Adaptation (Double ABCX model).

The model has three main parts: pre-crisis, crisis, and post-crisis (McCubbin & Patterson, 1983; Friedman, 1998; McCubbin *et al.*, 1993; Beckett, 2000; Boss, 2006). They are discussed in detail hereunder. The a, b, c and x variables of the ABCX model will be used in this section to describe the main parts of the model.

2.3.2.1 Pre-crisis

The pre-crisis includes the same factors present in the ABCX formula up to the crisis. The expanded model (Double ABCX) can be applied very well to situations whereby children are affected by HIV/AIDS.

The *a* factor (initial stressor), is equivalent to *A* in the ABCX formula (Hills, 1958); it is the parental diagnosis of HIV/AIDS. The *b* factor (the existing resources) is equivalent to the *B* in the ABCX formula. This includes the psychological/individual and social/community resources as well as intrafamilial/family resources that the family has to deal with the stressors prior the crisis (McCubbin and Patterson, 1983).

The *c* factor is the perception the family has on the illness. If the family views the illness as a challenge, it might be easy for them to cope with it, but if the illness is viewed negatively, there would be problems of adaptation.

2.3.2.2 The Crisis

The *x* factor is the crisis and is equivalent to the *X* in Hill's (1958) ABCX formula.

2.3.2.3 The post-crisis

The post-crisis variables of the Double ABCX model include the pileup of stressor on top of the initial stressor (*aA*); existing and new resources (*bB*); perception of initial stressor, pileup, and existing and new resources (*Cc*); coping; and adaptation to the post-crisis variables (*Xx*) (Boss, 2006).

2.3.2.3.1 The pileups (aA)

The pileups are the demands families deal with during crises. They may emerge from individual family members, the family system or the community to which the family belongs. There are five types of strains and stressors that families deal with when in crisis: (1) The initial stressor and its hardships. (2) Normative transitions. (3) The consequences of family efforts to cope with the illness. (4) Prior strains, and (5) ambiguity within the family and within the society (McCubbin & Patterson, 1983; Boss, 2002, 2006).

Stressors and Hardships (demands on resources): The hardships experienced by wives whose husbands were missing included when they had to play a dual role (i.e. of being both mother and father) requiring them to make decisions alone on matters such as disciplining of children, handling of family finances and managing children's health problems. Many experienced emotional, social and physical problems. Children in families affected by serious/chronic illness might also experience hardships when they are expected to play a dual role. Their level of development might also make matters difficult as they may not have developed adequate skills for the role. Age was found not to contribute towards the development of depression in families caring for a relative with dementia. Some studies found that adult daughters had a greater caregiver burden scores as compared to distant relatives (Prosser, Lamarand, Gebremariam & Wittenberg, 2014)

The calculation of stressor pile-ups varied between researchers, with some viewing it as the number of stressful life-events, whereas others used it as perceived caregiving burden or child characteristics (age, adaptive skills, challenging behaviour, level of disability, etc.) (Frishman, Conway, Andrews, Oleson, Mathews, Ciafaloni, Oleszek, Lamb, Matthews, Paramsothy, McKirgan and Romitti, 2017). In this study the pile-ups refer to the perceived caregiving burden and the child's age and sex.

Normative transitions: Normal transitions also place demand on the family unit since they require change. They occur simultaneously, but independently from the original stressor. Examples include: normal growth and development of children, adults, extended family members (e.g., death of a grandparent, births) and family life cycle changes. Families affected by HIV/AIDS are also not immune from the transitions.

Prior strains: The unresolved hardships prior the stressors contribute to pile-up of demands families must deal with. In the case of a missing husband, the wife became more aware of the unresolved conflicts with the in-laws, or parent-child relationship problems. The same could be experienced in families of an ill parent.

Consequences of family efforts to cope: The efforts the wives made to deal with the stressors were to seek emotional support from outside. The in-laws in particular did not like the method and thus added to the pile-up of the stressors.

Ambiguity within the family and society: Ambiguity occurs when the family members are not sure as to who is inside the structure both physically and psychologically and who is outside (Boss, 1977, 1980). Having a missing spouse is ambiguous since his or her return is not predictable. The same could apply in the case of an ill parent; not knowing when he or she will be healed and be back to his or her normal functioning is also ambiguous. The adequacy and efficiency of the solution the community or culture provides also contribute to the family's ability to manage stress.

2.3.2.3.2 Existing and new resources (bB).

In the Double ABCX model, the resources are the family's capabilities to meet the demands and needs. They include the individual, family and community characteristics.

Existing resources (b of the bB factor) are already present in the family and minimise the impact of the initial stressor and prevent the family from entering into a crisis. Examples include among others: individual characteristics e.g. ability to nurture, manage the home, engage in hobbies, recreation, or work; family characteristics like togetherness, role flexibility, shared values, and expressiveness; community characteristics such as friends, religious involvement, and mental health professionals (McCubbin & Patterson, 1983; McCubbin & McCubbin, 1996).

New resources (B of the bB factor) comprise the resources that the family develop or strengthen in response to the crisis or the pile-up. They include educational opportunities, increased self-esteem and self-sufficiency, reallocated roles and responsibilities, new communities, new-families, and community groups and clubs (McCubbin & McCubbin, 1996; Beckett, 2000).

Social support is the most important resource of the bB factor. Families with good social support are not only resistant to a major crisis but are able to bounce back and restore stability. Although most families develop new resources following a major crisis, it is however difficult in the HIV/AIDS infected and affected to access these resources due to stigma, thus making it difficult for the individual family members to be resistant and resilient (Betz & Thorngren, 2009).

2.3.2.3.3 Family definition and meaning (cC factor)

The Cc factor is the definition that the family gives to the stressor that caused the crisis, the pile-ups, existing and new resources, and the estimates of what needs to be done to bring the family back to stability. Families who redefine their crisis situation as a “challenge”, as an “opportunity for growth”, or just believing it is the Lord’s will coped better and were able to restore a balance in the family system (McCubbin & Patterson, 1983; McCubbin & McCubbin, 1996; Boss, 2006)

2.3.2.3.4 Coping

Family coping involves efforts to manage various dimensions of family life at the same time. It is not stressor specific. How well a family copes, influences how well it adapts. The family’s efforts to cope may focus on five areas: (a) Eliminating and/or avoiding stressors and strains; (b) Managing the hardships of the situation; (c) Maintaining the family system’s integrity and morale; (d) Acquiring and developing resources to meet demands; and (e) Implementing structural changes in the family system to accommodate the new demands (Boss, 1988).

2.3.2.3.5 Adaptation (xX factor)

In the Double ABCX model adaptation refers to an outcome because of change in the family system, which evolves and is intended to have long-term consequences involving changes in family roles, rules, patterns of interaction, and perceptions (McCubbin & Patterson, 1983). Family adaptation means that the family is able to cope with the demands of the crisis. It consists of a continuum of balances in functioning at two levels: the member-to-family (in which the demands of one member can be met by the family unit, or when the demands of the family unit can be met by the family members) and family-to-community levels (in which the demands of the family can be met by the community, or when the demands of the community can be met by the community). Adaptation conceptualised as balance or fit, can range from bonadaptation (healthy adaptation) to maladaptation (unhealthy adaptation) (McCubbin *et al.*, 1993; Beckett, 2000; Boss, 1999, 2002; VanBreda, 2001).

In this case adaptability would mean that the family will not present with severe grief. The changes will remain, but the family will be able to cope with the rearrangements. It is further described as the ability of the family to utilise the available resources to meet the demands of the stressor. In this way, families are able to assign meaning to their situation, to develop their own identity irrespective of the diagnosis and to establish relationships with the external environment

Although Hill's ABCX model has variables similar to those of the double ABCX, the latter has the post crisis variables that explain and predict how families recover from crisis and why some are better able to adapt than others. Adaptation is a dynamic process which depends on the illness stages. Beginning from the time of diagnosis, treatment and until death in case of life threatening illnesses (Velez, Palacio, Moreno & Krokaron, 2013). This research aims to identify qualities that help the affected families to bounce back following the member's HIV/AIDS diagnosis, thus the double ABCX model is adopted as the theoretical framework of this research.

2.4 CONCLUSION

This chapter gave a background of the Resilience Model of Family Stress, Adjustment, and Adaptation which is Reuben Hill's ABCX model, its origin, application to ambiguous loss, and expansion to the double ABCX model. The double ABCX model is expanded from Hill's 1958 model by adding the post-crisis variables. The post-crisis variables include the pile-ups (which are the demands the family deals with during a crisis), the meaning and definition the family gives to the crisis, the efforts the family make to cope with the crisis, and the family's adaptation (which could be healthy or unhealthy).

CHAPTER 3

LITERATURE REVIEW

3.1 INTRODUCTION

This chapter will present the literature on the work done in relation to ambiguous loss, grief and family resilient factors. Ambiguous loss will be discussed within the context of HIV/AIDS, grief, attachment theory and assumptive world theory. It will further present the rationale for grief diagnoses and research conducted in this field to identify different kinds of grief. Studies on the influence of family qualities in coping with adversity will include a positive outlook, sense of coherence, spirituality, family organisational patterns, communication processes, and financial support.

3.2 AMBIGUOUS LOSS WITHIN THE CONTEXT OF HIV/AIDS

According to Boss (2006), ambiguous loss refers to the experience by affected members of a sick family member who, due to a debilitating ailment, is experienced as if he/she is no longer with the family. This happens in situations where an ailing member could be so sick that they are no longer able to do their normal work and are seen as being psychologically absent or sometimes not being able to connect with the family at an emotional level or due to dementia as a result of the condition suffered. The experience of ambiguity with the presence or absence of the family member can be experienced as anticipatory loss. Such grief is defined as the distress and related emotions, cognitions, and behaviours that occur before an expected loss. Family members infected by HIV/AIDS may be experienced as psychologically absent and physically present as they progress in the development of AIDS.

The impact of watching a family member deteriorating from HIV/AIDS can be very traumatic. Nurses working with HIV/AIDS patients were reported to have a high likelihood to experience HIV/AIDS caregivers' stress syndrome typical to signs and symptoms of post-traumatic stress disorder (Shorter & Stayt, 2010; Mallison, 2013). The traumatic nature of the memories of the infected result in their grief process being suppressed, interrupted or prolonged (Boss & Carnes, 2012)

The responses of individuals working with and having lost patients to AIDS are exaggerated fears of contagion, recurrent nightmares and flashbacks, intrusive thoughts and dreams with images of death, relentless anxiety, avoidance of people with HIV/AIDS, swings between emotional numbing, flooding and detachment, and self-neglect and self-destructive behaviours (Shorter & Stayt, 2010; Mallison, 2013). Family members affected by HIV/AIDS could be in the same position as the professional caregivers and the experience of trauma symptoms by the affected families may be highly possible.

Experiences of such symptoms by affected family members emanate from the family's continuous fear of the impending loss of their sick family member. The fear is continuous and with no actual death coming through there is no closure but anticipation of such death keeps the family under immense stress. Boss (2006) refers to such anticipation as a source to perpetuate boundary ambiguity where the sick member's role in the family is no longer clear. Children have to take over the parental role unprepared and this happens with or without disclosure of the illness with a glaring physically deteriorating sick member from opportunistic HIV/AIDS related ailments.

3. CONTEXTUALISING AMBIGUOUS LOSS WITHIN THE CONCEPT OF GRIEF

The current research attempts to establish ambiguous loss in adolescents/children affected by HIV/AIDS. Ambiguous loss could lead to different types of grief for example disenfranchised, frozen, prolonged, anticipated, and chronic sorrow that will be discussed in detail in the sub-sections that follow (Boss, 1999; Doka, 1989; Olshansky, 1962)

Ambiguous loss is a loss that remains unclear. For the family who experiences ambiguous loss, the situation is stressful and oftentimes cruel in its unending torment (Boss, 1999, 2002). Although such loss is similar to grief, the difference is that with ambiguous loss, families struggle in defining the losses and creating meaningful narratives about the loss. Closure is difficult as rituals may not be performed (Boss, 2002). According to Boss and Carnes (2012), ambiguous loss is inherently open ended. Instead of finding closure, the therapeutic goal should be to help people find meaning with their loss. This differs from

Kubler-Ross's linear stages of grief, where one is expected to find closure after going through those stages (Bonanno, 2009; Kissane & Bloch, 2003; Boss & Carnes, 2012).

Ambiguous loss takes a toll on family members physically (for example fatigue, sleep disruptions, headache or stomach ache), cognitively (for example, preoccupation with the loss, forgetfulness, dreaming about the loss, or worrying), behaviourally (for example quietness, crying, talkativeness, withdrawal, dependence or avoidance) and emotionally (Boss, 1999; Betz & Thorngren, 2009). Ambiguous loss results in different types of grief, for example with Alzheimer, the disease is terminal even though the patient may live for years, the family anticipates what is to come and grieves early. Their grief is however disenfranchised because rituals of support are done only after death, thus frozen grief results (Boss & Carnes, 2012; Parkes, 2006).

O'Brien (2007), in his study on ambiguous loss in families of children with Autism Spectrum Disorders, both qualitative and quantitative results show that more than half of parents of children diagnosed with ASD, experience conflicting realities and emotions: fear and hope, helplessness and determination, frustration and joy.

3.4 CONCEPTUALISATION OF AMBIGUOUS LOSS

3.4.1 Ambiguous loss and assumptive world theory

Cognitive theories tend to focus on the schemas that people use to represent the world around them. Parkes (1971) used the term, assumptive worlds, to explain people's expectations and assumptions about their world. Included in the assumptive worlds are the person's important relationships, as well as personal beliefs and assumptions concerning the future and the self.

Parkes theorised that a sudden or dramatic change related to the person's assumptive worlds has the potential to produce a grief-like response. The theory extends the notion of a grief reaction to a broad range of negative events including the loss of a job (Archer & Rhodes, 1993). This theory provides an important rationale for extending grief research into

other areas of important losses in people's lives, including losses associated with chronic illness.

Janoff-Bulman (1989) extend the use of the assumptive world's theory to traumatic life changes. When one experiences traumatic events such as an accident or a disaster, his/her assumptions about the world as a safe and secure place are at risk. Her theory provides an important understanding of individual variability within a person's grief response (Archer, 2008). Rather than focusing only on the typical grief response, the context of the person's loss begins to take on great importance.

3.4.2 Ambiguous loss in the context of attachment theory

Bowlby's (1973, 1980) attachment theory provides insight into why some individuals develop severe grief reactions. According to this theory, grief is a deficit reaction to separation from the attachment figure. The experience in ambiguous loss due to chronic illness of a family member could have similar deficit reactions caused by forced detachment. According to Bowlby (1980), an individual's reaction to such premature detachment is to incorporate a picture of the figure along with the goal of attempting to stay close to the figure. The individual will initially protest the separation from the loved one, which results in anger and anxiety. When protest fails to restore proximity because of death, despair takes over with expressions of depressed mood, decreased appetite, etc.

Two attachment styles, the anxious and avoidant are linked to grief reactions. Bereaved individuals with anxious attachment are likely to experience intense anxiety, anger, sorrow, yearn inconsolably for the lost, fail to accept the loss, and have difficulties in establishing a new life structure. The pattern is termed chronic grief. On the other hand, those with avoidant attachment present with prolonged absence of conscious grieving as they avoid emotional expression of feelings towards the deceased (Kissane, Zaider & Schuler, 2012)

Delespaulx, Ryckebosch-Dayez, Heeren and Zech (2013) assessed grief reactions in individuals following the death of a partner to determine how the attachment style contributed to the intensity of grief. They found that individuals who reported anxious attachment to their spouses presented with high levels of grief reactions, and the attachment avoidance was found to present with fewer grief reactions. This research will

also assess the qualities in the family that influence the level of intensity of the adolescents' reactions and how they bounce back following adversity.

3.5 Rationale for grief diagnosis

The present study aimed at looking into grief reactions within ambiguous loss. The following is a discussion on the impact of loss on individuals and how they process grief within the context of Kubler Ross' five stages of grief. This will be followed by the various forms of grief following ambiguous loss and the rationale for making such diagnoses in the various events of families suffering following diagnoses of a life threatening disease and their reactions to the adversity.

3.5.1 Diagnosis within the five stages of grief by Kubler Ross

The reactions to the impact of loss on individuals within the context of Kubler-Ross' five stages of grief involves the expected stages that the affected person goes through during grief. These stages should however, be seen as a general guide to understand how people grieve but should be seen not as fixed and thus could follow any sequence

The first stage is that of shock wherein the affected member reacts in the beginning by showing intense shock at the news and may appear dazed at first refusing to believe the diagnosis; this is followed by anger characterised by frustration, irritability that they are ill. The anger may also be directed to God, their fate, a friend, a family member or to self.

The next stage is bargaining stage wherein the affected may start negotiating with friends, physicians and even God. They will promise to be good e.g. compliant, non-questioning, cheerful or promise to do charity work and attend church regularly so that they may be cured. Depression stage is characterised by patients showing irritability or sadness, psychomotor retardation, sleep disturbances, social withdrawal, hopelessness, worthlessness, and possibly suicidal ideations. Acceptance is the last stage wherein the beginning of the realisation that that death is inevitable sets in and those affected accept the universality of the experience. Under normal circumstances, patients are able to talk about facing the unknown (Kubler-Ross, 1969; Kubler-Ross & Kessler, 2005).

3.5.2 Prolonged grief disorder (PGD)

Prolonged grief disorder (PGD), also referred to as complicated grief disorder (CGD) is described as a pathological form of bereavement–related psychological distress (Kaplan & Sadock, 1998, 2008). Although the word ‘prolonged’ captures the nature of the disorder, it does not imply that the duration is the only indicator, but that as compared to bereaved survivors, the PGD sufferers are essentially stuck in a state of chronic mourning (Elvira de la Morena & Cruzado, 2013; O’Connor, Wellisch, Stanton, Olmstead & Irwin, 2012; Sullivan & Miller, 2015). According to these authors, the PGD sufferers feel bitter over the impending loss and desperately wish for the time they had together with the infected person and thus continuously become preoccupied with their sorrow and feelings of emptiness and helplessness.

Guarnerio, Prunas, Della Fontana and Chiambretto (2012) studied a sample of 40 caregivers of patients in a vegetative state and found that 15% of them had prolonged grief disorder. Leonardi, Giovanetti, Pagani, Raggi and Sattin (2012) found 27.6% cases of PGD in a sample of 487 caregivers. Chaimbretto, Moroni, Guarnerio, Bertolotti and Prigerson (2010) reported 35.6% PGD in a sample of 45 caregivers of patients in vegetative state (VS), and Elvira de la Morena and Cruzado (2013) found 60% cases of PGD in a sample of 53.

3.5.3 Prolonged grief and its overlap with other clinical syndromes

Some overlap has been noted between the clinical manifestation of PGD and PTSD as here are similarities in the experiences of intrusive thoughts, avoidance and numbness for both conditions. Some major differences need to be highlighted in that in PGD, reaction to bereavement is characterised by horror or fear and its intensity is connected to the closeness of the relationship with the patient, while in PTSD it rather reflects the traumatic nature of the event; intrusive thoughts tend to be different in nature; avoidance and hyper arousal, although present in PTSD, seem to be less characteristic of PGD (Guarnerio *et al.*, 2012 ; Kean, 2010; O’Connor *et al.*, 2012; Chiambretto, Moroni, Bertolotti & Prigerson, 2010).

For depression as well, the differential diagnosis with PGD can be complicated because of the high rates of comorbidity between the two conditions. Deflected mood, psychomotor

retardation, and decreased self-esteem are more closely connected to depression, while the sense of yearning, disbelief over the death, feeling empty and meaningless, difficulties in thinking about the future, feeling stuck and lost are more specific related to PGD (Boss & Carnes, 2012).

The similarities highlighted between the clinical syndromes of PTSD and depression with PGD, indicate the seriousness of ignoring PGD in the population. This could be mental illness in progression and could, on being identified early, become contained and intervention be tailored before it complicates. The present study aims thus to survey the extent of the suffering by those affected by HIV/AIDS and through inherent silence approach around the condition among families and especially if the disclosure is not forthcoming, identify those who can benefit from the relevant intervention.

In a study by Guarnerio *et al.* (2012) and Chiambretto *et al.* (2010) on the prevalence for PGD among caregivers of a vegetative state (VS), the authors hold the view that caring for the family member in a vegetative state is considered very stressful and that the carers experience chronic mourning with intense longing and yearning for their vegetative state relative. These symptoms may not be accounted for by MDD and PTSD, but could be framed within PGD (which is not yet included in the DSM).

The focus on grief reactions in the present study is guided by the fact that affected families of vegetative state patients as described above could have similar reactions as those of families affected by HIV/AIDS and other chronic diseases. In most cases carers of HIV diagnosed family members who may not have disclosed may suffer in silence. This phenomenon has not been directly investigated as to which specific symptoms would such a group present with, making intervention impossible or too broad to address the real symptoms or the issues to assist the family to continue with the role of caregiving.

The present study thus aims at surveying the extent of grief reactions among the HIV affected families as a way to gauge the extent and direction which psychological intervention should be directed. People in grief have low energy and could even have comorbid conditions of depression and PTSD, which are bound to make the caregiving

process even more difficult, considering the emotional load associated with ambiguous loss situation presented by being affected by the disease.

3.5.4 The concept of Anticipatory grief

Anticipatory grief occurs before the death of a family member. In the case where one is sick, the patient and the family members anticipate that the sick one will one day die and they start to grieve for his/her death. The intensity of the grief reactions increases with the progression of the illness. It is also influenced by the developmental levels of the persons affected and the specific types of illness (Rando, 1993). If it is expressed openly and adaptively, grief after the death may be less intense and distressing for carers (Chan, Livingston, Jones and Sampson, 2012). Anticipatory grief is also described by other researchers using themes of ambiguity and anticipation (Adams and Sanders, 2004).

Children affected by HIV/AIDS may suffer prolonged anticipatory grief, an isolating and painful process during the period the parents become ill and ultimately disabled (Chi & Li, 2013). In a study by Chan *et al.* (2012) on grief reactions in dementia carers, they found that carers experience anticipatory grief as multiple losses for themselves (companionship, personal freedom and control) and the person with dementia. Anticipation and ambiguity about the future, anger, frustration and guilt were the common features. Carers' depression was found to increase with anticipatory grief. Several studies were compared by Chan *et al.* (2012) and one of the two studies reports the prevalence of anticipatory grief as 47% (O'Connor *et al.*, 2012) and 71% (Ross & Dagley, 2009). Anticipatory grief was found to occur twice as often in cardiac carers as compared to dementia carers (Ross & Dagley, 2009).

This concept of anticipatory grief is relevant to the current research as carers of HIV/AIDS and other chronic diseases may anticipate the death of the loved one once such a diagnosis is made. The stigma that comes with the diagnosis and the developmental levels of the carers could affect the intensity of the reaction. This study attempts to identify the grief reactions in the adolescent carers and to determine if the intensity will be similar to those of other chronic illnesses.

3.5.5 Disenfranchised grief

Disenfranchised grief is the grief that persons experience when they incur a loss that is not openly acknowledged, publicly mourned or socially supported. For example: (a) In cases where the relationship is not socially recognised, for example the death of an ex-lover, or a lover in extra-marital affair, or termination of a friendship; (b) The loss is not socially recognised as a legitimate loss. (c) The griever is not socially recognised due to some specific characteristics (Kaplan & Sadock, 2008; Jeffreys, 2005; Melhem & Brent, 2011; Valentine, 2008; Sullivan & Miller, 2015)

In all these instances, the griever is denied social support which is deemed important for the successful alleviation of symptoms. The griever may experience common grief reactions, especially isolation, hopelessness, anger, resentment, guilt, self-condemnation, and ambivalence, which may become chronic and unresolved (Doka, 1990; Sullivan & Miller, 2015). This is especially true if the loss is socially stigmatised such as the loved one suffering from AIDS. Lesbian, gay, bisexuals and transgendered people may not have their losses validated because they are a marginalised group (Harner, Henz & Evangelista, 2011).

This study will compare the experiences of anticipatory grief in individuals affected by HIV/AIDS with those affected by other chronic illnesses such as cancer.

3.5.6 Frozen grief experience

Ambiguity in ambiguous loss can immobilise and traumatise those affected. Because the loss is unverified, families are left on their own and due to the prevailing ambiguity, relationships dissipate as friends and neighbours do not know what to do or say to families with unclear losses. For all of these reasons, ambiguous loss is a relational disorder and not a psychic dysfunction and with the ambiguity rupturing the meaning of loss, people become frozen within the space of trying to cope as they experience the grief (Boss, 1999, 2002, 2006).

Examples of this kind of grief are seen in persons with dementia, due to the disenfranchisement of the loss, the affected members' grief is frozen. This study will explore the presence of grief in children affected by HIV/AIDS and other chronic disorders.

3.5.7 Chronic sorrow

Chronic sorrow refers to the ongoing feelings of sadness due to chronic or permanent loss (Roos, 2002). Because the loss is a permanent part of the person's life, chronic sorrow continually requires energy from the person to negotiate the demands of the loss. The person must also deal with the cyclical and ongoing nature of the psychological and emotional reactions. Whereas normal grief is precipitated by the death of a significant other, chronic sorrow is brought on by the permanent loss of a significant relationship. This could be related to the birth of a child with disabilities (physical or psychological) or the diagnosis of a chronic illness (Eakes, Burke & Hainsworth, 1998).

Copley and Bodensteiner (1987), in their study of chronic sorrow in families of disabled children, found that parents of most disabled children's emotions ranged from periods of happiness with relationship to pain and sadness following internal or external triggers which remind them of the losses. They were not able to bring closure, but the fluctuation of moods helped to maintain the cyclical nature of the problem.

According to Boss & Carnes (2012) and Sullivan & Miller (2015), although people with chronic sorrow present with symptoms similar to those of depression, they are not clinically depressed. Their sadness requires human connection and social support to help people come to a meaning, unlike in depression where intervention is aimed at alleviating symptoms.

Social support may be difficult for the family to find. Symptoms accompanying depression include negative impact on one's social, occupational or academic function. These are easily identified and can draw the attention of most people, unlike with chronic sadness where one's functioning may not necessarily be impaired. Social support is received in the beginning when a diagnosis is made, but as the illnesses becomes chronic, people may be tired of giving support or there could be other matters that require their attention, hence the

lack of social support. Taking care of a chronically ill person may go on for years. Friends and neighbours may not have the desire and stamina to make that long-term commitment. This is similar to disenfranchised grief as the affected has very little normal support as the loss tends to be unrecognised by the society (Roos, 2002; Kaplow, Layne, Saltzman, Cozza & Pynoos, 2013).

Ahlstrom (2007) examined the experiences of loss and chronic sorrow in persons with severe chronic illnesses. Semi-structured interviews were used to gather data related to loss and chronic sorrow. The researcher included in the study 30 Swedish adults between the ages of 18 and 64 years who were coping with severe physical disease or injury. The assessment determined that 53% of the participants had experienced at least four of six criteria of chronic sorrow. Most of the participants in this study are on ARV treatment, which makes them live longer. It is envisaged that people affected by HIV/AIDS can also experience chronic sorrow due to their having to deal with the complications of side effects and the adult roles that they pre-maturely assume. This research thus explored the experiences of ambiguous loss and the family qualities that could have a moderating effect on the experiences of ambiguous loss and grief.

6 THE INFLUENCE OF FAMILY QUALITIES IN COPING WITH ADVERSITY

Studies have shown that family resilience has a positive influence on how families respond to adversity in their environment. The family resilience framework gives a structure for exploring family responses with a particular focus on strengths (McCubbin *et al.*, 1996).

The adaptive resources are the existing or expanded resources that are strengthened as a way to respond to the pile-ups or demands posed by the stressor event. They either reduce the demands on the family or help the family adapt to the changes. They can be the personal family system or the social support. The results of this study show that the adaptive resources that were found to be available in the families affected by HIV/AIDS or cancer were family hardiness, family and friend support, and F-COPES.

Resilience factors that were found to make families adapt to stress in the environment include: a positive outlook, sense of coherence, spirituality, family hardiness, cohesion and

adaptability, family member accord, communication, time together, mutual recreational interests, routines and rituals, flexibility, financial management, and social support (Truffino, 2010; Ungar, 2011; McCubbin & McCubbin, 2001; Black & Lobo, 2008; Truffino, 2010; Saltzman, Lester, Beardslee, Layne, Woodward & Nash, 2011). It is believed that if family members understand these strengths, they will be able to understand the nature of stressful events and recognise changes within the family. The adolescents were the ones interviewed during this research as such factors that influence their resilience in the families will be discussed.

3.6.1 Positive outlook

A positive outlook plays a vital role in coping with stress, recovering from a crisis and overcoming barriers to success. Hope is based on faith; it fuels energy and strength to rise above adversity. Studies found that a positive outlook enhance the quality of life and important relationships (Walsh, 1998; Black & Lobo, 2008). Families dealing with life threatening illnesses are likely to lose hope. It was however found in research conducted by Greef, Vansteenwagen and Geldhof (2014) that positively redefining the stressful situation was positively linked to family resilience.

3.6.2 Sense of coherence

Families with a shared sense of coherence do well when faced with adversity (Antonovsky, 1993; Hansson & Cederblad, 2004) by seeing a crisis as a challenge that is comprehensible, manageable and meaningful to deal with. Various research studies that were conducted with families affected by cancer to assess the impact of family types on coping, found that members whose families have high cohesiveness and above average expressiveness, carry the lowest rates of psychosocial morbidity and grief (Kissane & Block, 2003; Mitrani *et al.*, 2012).

On the other hand, children whose families are characterised by high conflict and low cohesiveness become symptomatic (present with depression and anxiety). The stress of acute grief is associated with increased family dysfunction (Melhem & Brent, 2011; Feaster, Brinks, Robbins & Scapocznik, 2010).

3.6.3 Spirituality

According to Marks (2004), spirituality involves a shared belief system of hope and triumph that helps the families to give meaning to a stressor. Fundamental beliefs in the families have religion and spirituality as their foundation. Spiritual aspects such as hope, dignity, and meaning in life were found to protect one from suffering and foster well-being (Krikorian, Limonero & Corey, 2013).

Spirituality may or may not be religion based, but whatever the spiritual orientation, families associated with a shared internal value system that provides meaning tend to feel a connection with the family, community and the universe (Walsh, 1998, 2009; McAdoo, 1999).

According to Walsh (2009), faith, prayer and meditation, and congregational involvement have been found to be wellsprings for resilience. He further argues that spiritual nourishment can also be found through deep connection with nature, secular humanism, creative expression in music and the arts, and social activism.

A research done on post-traumatic growth revealed that a crisis can yield learning, transformation and growth in an unforeseen direction (Tedeschi & Calhoun, 2004). Spirituality allows children to view adversity as an opportunity for personal growth and development (Pienaar, Swanepoel, Van Rensburg & Heunis, 2011; Skovdal & Daniel, 2012). It can help family members to acknowledge the importance of loved ones and to heal old wounds.

3.6.4 Family organisational patterns

3.6.4.1 Connectedness

Prolonged adversity or crisis might shatter the family's cohesion, resulting in members not trusting each other for support (Walsh, 2011, 2016). Family connectedness is thus another factor that could help to restore relationships through mutual support, collaboration, and commitment to each. The observation was made where there is a threat of death or loss,

aging parents and their adult children often develop new perspectives for resolving old conflicts to achieve greater mutual understanding (Walsh, 2011, 2016). Being together as a family was found to be one of the key factors in families caring for a child with cancer, this was further supported by a significant correlation found between family time and routines and family adaptation (Greef, Vansteenkamp & Geldhof, 2014).

3.6.4.2 Flexible structure

Flexibility is core in resilience and it involves the ability of the family to rebound and reorganise when faced with a challenge while maintaining a sense of continuity (McCubbin & McCubbin, 1996). Although most families prefer structure and order, it is best if there is a balance between moderate structure and flexibility. In moderately structured relationships, there is democracy in which each member is allowed to raise his/her views, roles are stable, family rules are age appropriate, acknowledged and predictably enforced. In resilient families, change is not viewed with helplessness, roles are reorganised and change is viewed optimistically to attain equilibrium (Black & Lobo, 2008; Walsh, 2002; White, Richter, Koeckeritz, Munch & Walter, 2004).

In families caring for a member with chronic illness, the sick member's role of primary caregiving in most cases changes as the illness progresses. This leads to the family identifying who will then take the primary caregiving role. The role of the new primary caregiver will be made easy by the support he or she gets from others (relatives, family, friends, or other sources). The level of distress will also depend on the relationship the primary caregiver has with the patient. (Velez *et al.*, 2013; Krikorian *et al.*, 2013). The trusting relationship with the parent was found to be the most protective factor in children affected by HIV/AIDS (Wang, Li, Barnett, Zhao, Zhao & Stanton, 2012)

According to the results of a qualitative study conducted among caregivers of patients with cancer pain and those with non-cancer pain, the physical symptoms and pain the patient experiences, having little control over these symptoms, having difficulties to comply with caregiving, and perceiving the caregiving role as limiting their own lives were found to increase the level of grief and suffering (Velez *et al.*, 2013). Smooth transitions in care

arrangements were found to stimulate resilience in children affected by HIV/AIDS (Zhao, Zhao, Fang, Zhao, Lin & Zhang, 2011)

3.6.5. Social support

The ability to receive social support from families, individuals from community, and those from church were the key resilience factors in families caring for members diagnosed with cancer (McCubbin, Balling, Possin, Frierdich & Bryne, 2002; Sherman, Mcguire & Cheon, 2014). The authors further argue that it is not easy to have support available and to receive it. It is the responsibility of the families to seek the available support and use it.

In addition, the healthcare team was also found to be the source of support in families caring for a child diagnosed with cancer. Doctors are seen by these families as the life savers (McCubbin *et al.*, 2002) and the nurses and doctors' faith and openness and the information provided by hospital employees were reported to be helpful in weathering the stressful period of having a child diagnosed with cancer (Greeff *et al.*, 2014). Greeff *et al.* (2014), however, did not find a positive correlation between the external coping strategies and family adaptation in families caring for a cancer diagnosed child.

The support that the caregiver of a relative with dementia received, didn't buffer the symptoms of depression that the caregiver presented with. This support includes that from the healthcare team, local parish, and self-help groups. Patients with dementia often present with insomnia and this thus affects the sleeping patterns of the caregiver who will also wake up as the patient does. The other factor is that patients with dementia's cognition deteriorates, thus limiting their engagement with the caregiver. The caregiver will thus develop sleep disturbances and depression. It can thus be said that the condition of the caregiver seems to be the outcome of the actions and activities taken rather than the time devoted (Strivens & Craig, 2014; Malak, Krawczyk-Wasielewska, Glodowska, Grobelny, Kleka, Mojs, Keczmer & Samborski, 2016).

In a research on protective factors in children and families affected by HIV/AIDS, children whose parents were seen as caring were found to have a more positive health condition than those whose parents were perceived as uncaring (Betancourt, Meyers-Onki, Stulac, Barrera, Mushashi and Beardslee, 2011; Kapp & Brown, 2013).

3.6.6 Communication processes

Emotional expression and sharing bad news differ from culture to culture. Clear information giving, emotional expression, pleasurable interactions, collaborative problem solving and preparedness always foster resilience in families (Walsh, 1998).

Messages that are clear and congruent facilitate effective family functioning (Epstein, Ryan, Bishop, Miller & Keitner, 2003). Unclear and ambiguous messages lead to misunderstanding, confusion and anxiety. Families often avoid talking about painful or threatening issues like divorce or serious illness with the purpose of protecting the members from pain. However, the anxiety about the unspeakable can result in somatic or behavioural problems, especially in children (Walsh, 2011).

In families where there is open communication, mutual trust, empathy and tolerance for differences, members are encouraged to share their feelings aroused by crisis events or chronic illnesses (Black & Lobo, 2008; Walsh, 2011). This was confirmed by Greef *et al.* (2014), where family members caring for a cancer diagnosed child, reported open communication and assigning a positive meaning to a crisis as positive family attributes. There is, however, gender differences as in some cultures, men are prohibited from emotional expression. This leads to increased substance abuse, destructive behaviours, and relational conflict. Finding humor and laughter in the midst of a crisis was found to foster resilience.

Other factors found to be present in resilient families were the family's ability to collaboratively solve problems and conflicts. According to Linsey & Mize (2001) and Black & Lobo (2008), in well-functioning families, parents often act as mediators, expressing their own ideas, bringing out others' ideas and encouraging all other family members to express their feelings.

There is a difference in the experience of stress between men and women. The identity theory suggests that both men and women are more likely to experience stress when an important identity is threatened (Betancourt *et al.*, 2011).

The family qualities with regards to how families cope as a unit play an important role in determining how members pass through this stressful time. The study on the impact of divorce on teenagers indicates that teenagers from resilient families cope (Mashego & Taruvinga, 2014) and that the impact of divorce is moderated by family support for its members, rate of family togetherness and doing things together as a unit and hardiness.

In the present study, it is clear that members infected by HIV may not disclose to all members in the family at the same time. Such staggered disclosure does affect the family members differently and most of the effect of such illness on the family members is often seldom openly expressed and as such most family members may process the impact secretly and in silence.

Caring for HIV infected members can be stressful and this study aimed at highlighting family resilience factors that could moderate such impact on the caregivers. The complexity of the situation is the impact of HIV/AIDS on the members in a way that it makes them have prolonged fear of anticipatory loss of a family member and as such requiring inner capacity to deal with the impending loss. The present study thus aims to identify which factors would make the families adjust their functioning in the face of such adversity.

3.6.7 Family hardiness

Family hardiness was found to mediate the level of stress and family relationships in the studies by Weiss, Robinson, Fung, Tint, Chalmers and Lunskey (2013) on mothers caring for children diagnosed with ASD. This implies that chronic stress can have an impact on the family's internal and external resources which could affect the meaning the family attach to the stressor and thus the ability to cope. Setwaba (2015) found that family hardiness escalated the level of stress in families affected by HIV/AIDS. The internal strength and the meaning that the family gives to their demands seem to also buffer the grief. These findings are consistent with studies of parents of children with special needs (Frishman *et al.*, 2017; Pozo, Sarria & Brioso, 2014; McStay, Trembath & Dissanayake, 2014).

3.7 PSYCHOLOGICAL IMPACT OF CANCER DIAGNOSIS ON THE FAMILIES

A diagnosis of cancer puts the families immediately in a crisis situation. Parents described feelings of shock, disbelief, unreality and fear at hearing the diagnosis and being overwhelmed by a lot of information given by the healthcare providers regarding the type of cancer and treatment that the child should receive (McCubbin, Balling, Possin, Frierdich & Bryne, 2002).

The results however differ from those in caregivers of dementia diagnosed relatives. Most caregivers of dementia diagnosed relatives or parents suffer from chronic health problems, such as depression. Factors that contribute to the depressive symptoms include: (1) Sleeping problems, for example, dementia is often associated with sleeping disturbances, and this implies that when that happens, the caregiver will often be woken up in the night. (2) The illness, by virtue of dementia being a progressive illness, caregivers experience intense stress (3) Social isolation as caring for a demented relative requires devotion of time and attention to the relative; furthermore, with the progression of the disease, the demented relative may not be able to engage in an ordinary conversation (Malak, Krawczyk-Wasielewska, Glodowska, Grobelny, Kleka, Mojs, Keczmer & Samborski, 2016).

3.8 SUMMARY OF LITERATURE REVIEW

It is evident from previous studies that chronic illnesses and disabilities (physical and psychological) are related to ambiguous loss which results into some form of grief that can be explained in various ways as PGD, chronic sorrow, anticipatory grief, disenfranchised grief, and frozen grief. The symptoms for such grief reaction may be similar to those of pure grief, depression, or PTSD. Ambiguous loss is further seen as a relational loss with implications for the need for some social cohesion to assist affected members in their experience of impending loss of their sick family members. The impact of ambiguous loss that leads to grief in other chronic conditions is examined for HIV/AIDS and cancer, also the importance of the family qualities that could influence family resilience are highlighted for enquiry in this study.

CHAPTER 4

METHODOLOGY

4.1 INTRODUCTION

This chapter covers research methodological aspects used in the study. The research design, sampling procedures, instruments used for data collection and the psychometric properties are discussed. It further sheds light on the procedure followed in the collection of data and the statistical methods used. Ethical considerations employed in the study will also be shared.

4.2 RESEARCH DESIGN

The research design used in this study was quasi experimental using triangulation of both quantitative and qualitative methods for data collection. The ambiguous loss and grief reactions and the family moderating factors in adolescents from families affected by a parental HIV/AIDS diagnosis (experimental group) were explored and compared with those from families with a parental cancer diagnosis (control group). The independent variables were family qualities and the family adaptability was regarded as the dependent variable.

4.3 THE RATIONALE FOR THE CHOICE OF METHODS IN THE STUDY

Both quantitative and qualitative methods were required in the study to be able to measure (quantitative) grief symptoms, family qualities and use of semi structured interviews (qualitatively) to explore the in-depth feelings of 'anticipatory loss' around the illness of their family members in line with Boss (2006) that ambiguous loss is a perceptual phenomenon that is expected to change, and is best measured qualitatively.

The purpose of the triangulation of methods was to ensure that the findings through utilisation of different methods are validated. In this study the TRIG questionnaire was used to measure grief symptoms, whereas the resilience questionnaires measured family

qualities. At the same time semi-structured questions were used to explore the ambiguous loss and family resilience factors.

4.4 QUANTITATIVE PHASE

4.4.1 Sampling

Participants were sought from CANCER wards and ARV clinics at Pietersburg and Mankweng hospitals as well as two outlying ARV clinics that feed into Mankweng hospital, namely Makanye and Nobody clinics. A convenient sample of 159 participants participated in this study. Ninety-five of the sample came from families affected by HIV/AIDS and sixty-four were from a control group of families affected by cancer. The primary participant in each family was an adolescent child who was identified by the parent as playing a caregiver role in each group.

For the HIV/AIDS group, lay counsellors at different HIV/AIDS clinics assisted in identifying participants by checking the parents who had been diagnosed for not more than two years and had an adolescent child. For the control group, participants were sought from the cancer ward and oncology clinics. The researcher screened parents for adolescent children who became primary participants in the study.

The criteria for participation in the research included adolescents of age between 12 to 18 years old and also the fact that one did not have a diagnosis of any mental illness or significant cognitive impairment. Participants were black South Africans mainly from the Bapedi cultural group. This is the main ethnic group living in the area where the research was conducted viz. Capricorn District, Limpopo Province. They were included in the study irrespective of their religious denomination, sexual orientation or gender.

4.4.2 Procedure

Ethical clearance (No: TREC/34/2015) was obtained from University of Limpopo ethics clearance committee. Permission to conduct the study at the health facilities in the Capricorn district by identifying parents and their adolescent children for participation in the study was sought from the Limpopo Department of Health.

Data collection was done by first screening the target groups to determine if there were adolescent children in the family and the parents' consent for participation of the children in the study was obtained. Screening was done by four lay Counsellors and two intern Clinical Psychologists who were trained specifically to assist in the project. A biographical questionnaire was administered to parents who indicated that they had adolescent children.

Most parents consented to the inclusion of their children in the research project because they believed their children could benefit from talking about their distress. There were, however, those who refused to consent for participation of their children fearing that this might disturb their children. Some indicated that since their children did not know about their status, the interviews might make them suspicious.

Adolescents whose parents agreed to their participation and consented to their participation in the study were contacted telephonically and arrangements made for them to come to the clinic/ hospital on suitable days for the collection of data process. The adolescents, who agreed to participate, completed the assent forms. Trained research assistants assisted in the administration of questionnaires. The aim and purpose of the interview was explained to the participants and they were given time to ask questions and indicate if they were still willing to participate in the research or not. All the identified adolescents consented to the research participation. The researcher re-emphasised the issue of anonymity and confidentiality, and that if for some reason they did not feel comfortable to continue with the questions, they were free to say so.

Most participants preferred to respond to the questionnaire written in English. They were however encouraged to ask questions to clarify any points if there was a need to do so.

The sections in the questionnaire included biographical items, grief questions followed by family resilience questions. On average, it took 50 minutes to complete the questionnaires and those that needed a break in between were allowed to do so. Trained research assistants helped during the administering of the questionnaires.

4.4.3 Measuring instruments

The quantitative measuring instruments used were in two sections, viz. the biographical section and the scales section. The biographical section consisted of biographical questions designed by the researcher.

The scales section included the Family Attachment and Changeability Index 8 (FACI8) to measure the level of family adaptation and functioning; the Family Crisis Oriented Personal Evaluation Scale (F-Copes) (McCubbin and Patterson, 1983), as a measure of family coping; the GHQ-28 to measure depression and the quality of life of affected children respectively and the Texas revised Inventory of Grief (TRIG) (Kissane, Bloch, McKenzie, McDowall & Nitzan, 1997) to measure grief; The questionnaires were translated from English to Sepedi and back-translated from Sepedi into English to cater for those who did not understand English.

4.4.3.1 Biographical section

The questionnaires were the same for both the experimental group and the control group. Two biographical questionnaires were completed. One by the parents for screening purposes and the other one by the identified adolescent. The questionnaire for screening purposes consisted of age, gender, family income, level of education, place of residence, period of the diagnosis, whether the diagnosis was disclosed or not, number and age groups of children, and the perceived care giver.

The adolescent participants' questionnaire consisted of age, gender, grade, language, as well as the period of parent's illness

4.4.3.2 Texas Revised Inventory of Grief (TRIG)

The grief reactions of caregivers were measured by using the TRIG, which is a self-reporting questionnaire that assesses "normal" versus pathological grief symptoms. It was adapted and condensed from the Inventory of Grief scale by Faschingbauer, Zisook & De Vaal (1987). The TRIG consists of 26 items in 3 parts. The first part has 8 items that assess how the person was feeling at the time of death (time of death was announced), the

second part has 13 items that measure grieving thoughts and feelings at the present moment (time of data collection), and the last part consists of 5 items (answered by either yes or no) about an assortment of facts related to the death.

Each item in the first 2 parts is scored on a 5-point scale ranging from 1 (completely true) to 5 (completely false). High mean values on the items indicate a low level of grief (<50th percentile) and lower scores indicate more grief (> 50th percentile). High grief scores on both the past and present feelings indicate that the respondent has prolonged grief; a low grief score on both the past and present are indicative of absence of grief, whereas a low grief score on past feelings and a high grief on the present scale show that the respondent has delayed grief, and finally a high grief score on the past and a low grief on the present scale indicate acute grief. TRIG thus differentiates between prolonged grief, low grief, delayed grief and acute grief (Faschingbauer, Devaul & Zisook, 1987; Hansson, Capenter & Fairchild, 1993; Faschingbauer, 1981).

For this study, the TRIG was first translated into Sepedi and then back-translated into English to match the two English versions. A total of 13 items was used for the first 2 parts of the scale because the researcher anticipated that due to age, the participants may struggle to recall most of the past events and that the questionnaire was going to be too long for them to complete taking into consideration their attention span. The first 6 items (items 1-6) measured the respondents' initial reaction at the time of the illness. The second part (items 7-13) measures the present thoughts and feelings towards the ailing parent. Other amendments on the questionnaire included replacing death with illness and including the parent to be more specific on the infected. Both the past and present experiences were chosen because among other things the researcher wanted to identify the type of grief the participants were experiencing.

The TRIG was chosen because of the following reasons: it has been widely used and has shown to have good psychometric properties (Alpha coefficients are over 0.8 at time periods ranging from 2 to 30 months of death); it focuses on grief rather than broad psychiatric symptoms; it assesses normal rather than complicated grief; and considers grief across all possible losses, rather than a specific loss (Kissane *et al.*, 1997).

4.4.3.3 Family Attachment and Changeability Index 8 (FACI-8)

The FACI-8 developed by McCubbin and Thompson (1996), was used to measure the level of family adaptation. It consists of 16 items (6-point likert scales) divided into two subscales: The attachment subscale designed to ascertain the strength of family members' attachment to each other, and the changeability subscale used to ascertain the degree of flexibility between family members in their relationships with each other (Fleming, Jory and Burton, 2002). Reliability for the subscales varies between 0.75 and 0.80. Its validity was established by determining the FACI-8's relationship to the treatment programme's successful outcome (McCubbin *et al.*, 1996)

According to resiliency model, the outcome of all family processes result in varying degrees of family adaptation and functioning. The greater the level of adaptation and functioning, the more resilient is the family (McCubbin & McCubbin, 2001).

4.4.3.4 Family Crisis Oriented Personal Evaluation Scale (F-COPES)

The F-COPES instrument was created by McCubbin and Thompson (1991) to identify effective problem solving approaches and behaviour used by families in response to problems or difficulties. The scale focuses on two levels of interaction i.e. the individual to family system (the way the family manages crises internally amongst family members), and the family to social environment (the manner in which the family manages problems outside its boundaries, but that still have an influence on the family as a unit).

The F-COPES is a 30-item self-report instrument. Each item is answered on a 5-point Likert-type, with answers ranging from "strongly disagree" to "strongly agree". The instrument is conceptually organised for internal family coping patterns (three scales) and external family coping patterns (five scales). Scores may be obtained for each dimension or for the total instrument. Reliability for F-COPES was determined by Cronbach coefficient alpha (0.86 and 0.87) for two samples using test retest (McCubbin & Thompson, 1991). A high score is an indication of effective good coping behaviours.

4.4.3.5 Family Hardiness Index (FHI)

The FHI, developed by McCubbin, McCubbin, Olson, Lavee and Patterson (1985), measures the fortitude and durability of the family unit by evaluating its characteristics of hardiness on three subscales: The commitment subscale which measures the family's ability to work together, their internal strengths and their dependability; the challenge subscale which measures the families' ability to learn, positively reframe crises as challenges and to seek out new experiences as challenges; and the control subscale which measures the extent to which the family has an internal locus of control to be in control of their circumstances as opposed to being the victims of fate. The scale consists of 20 items which require participants to assess on a 4-point Likert rating scale, the degree (false, mostly false, mostly true, true, or not applicable) to which the statement describes their current family situation. The measure reportedly has an internal reliability of 0.82 and validity coefficient of between 0.15 and 0.23 (McCubbin & Thompson, 1991; McCubbin *et al.*, 1996).

4.4.3.6 Relative and Friend Support Index (RFS)

The RFS developed by McCubbin, Larsen and Oslon (1982) measures the extent to which the family uses support of friends and relatives as a coping mechanism. It consists of eight items about sharing problems or seeking advice from neighbours or relatives, each requiring a 5-point linkert rating scale response ranging from "strongly disagree" to "strongly agree". This index has an internal reliability of 0.82 and validity coefficient of 0.99 (McCubbin *et al.*, 1993)

4.4.4 Data analysis

Analysis of the quantitative data were done using the Statistical Package for Social Sciences (SPSS version 22.0) for descriptive and inferential statistical tests. Descriptive statistics were used for biographic data and statistical tests were conducted to compare the experimental and control groups. The Chi-Square, T-tests, ANOVA were used in the study to show associated variables and significance of differences between variables. Regression analysis was used to determine the predictability of variables to show the moderating effect

of resilience on the impact of the experience of an ailing member of the family. Pearson correlation was also used to identify the significance of potential resilience factors that are present in families caring for both HIV/AIDS and the cancer diagnosed parent (s).

4.5 QUALITATIVE PHASE

4.5.1 Sampling

The sample consisted of 159 participants. Ninety-five (59.8%) of the participants were from families affected by HIV/AIDS, whereas sixty-four (40.3%) were adolescents from cancer affected families. The same group of participants for the quantitative data continued with the qualitative responses since their responses were done alongside the quantitative questions.

4.5.2 Procedure

The adolescents who participated in the study were interviewed using semi-structured open-ended questions that elicited qualitative responses on their feelings towards the illness of the parents, the role they are playing now that the parent is sick, feelings towards the role, disclosure, and the family qualities that they think help during this ailing period. The questions were asked in Sepedi, recorded verbatim and later translated into English for the purpose of analysis.

4.5.3 Data analysis

For the qualitative data, a thematic content analysis was done. Data were broken down into meaning units. The meaning units were coded. To increase the stability and reliability of data, the coding process should be done repeatedly (Downe-Wambolt, 1992). Themes and sub-themes were selected and coded, whilst unnecessary and unrelated themes and sub-themes were eliminated. The researcher identified the frequency of the themes that emerged from the data and converted them into percentages. To ensure quality of the analysis, tables were used for recording the themes and the researcher asked a more experienced researcher to also analyse the results independently. On completion, the

researcher and the co-coder discussed the coding and agreed on the categories to ensure trustworthiness (Burnard, 1991; Downe-Wambolt, 1992).

4.6 ETHICAL CONSIDERATIONS

The following ethics were considered prior to the research being conducted.

4.6.1 Permission

Different structures were consulted for permission to conduct the research. This included the research ethics committee from the University of Limpopo for ethics clearance, Limpopo Department of Health and institutions where the research was conducted for access clearance. Informed consent was requested from the parents and assent from the children prior to administering of questionnaires.

4.6.2 Informed consent

Respect for persons demands that the participants enter into the research voluntarily and with adequate information. Informed consent was provided to the parent participants prior to beginning the interview. The researcher reviewed the contents of the consent with each participant to ensure understanding. Information in the informed consent covered the following items: the research procedure, the purpose of each, risks and anticipated benefits, alternative procedures (where therapy is involved), and they were also offered an opportunity to ask questions and to withdraw at any time from the research. The informed consent was written in lay language to avoid any technical jargon, for the participants to understand. (A copy of the informed consent is found in the appendices)

The consent was sought from the parents prior to the children consenting themselves, as per section 71 of the National Health Act. According to this Act, written consent from a parent or a legal guardian must be sought in conducting research with all minors below the age of 18. Children whose parents gave permission for their inclusion in this research, consented prior to their being included in the research. Those parents and children who did not consent were not included in the study. Some parents felt participation in the study

would traumatise their adolescent children. For younger children, due to their age and cognition, a verbal consent was given.

4.6.3 Confidentiality and anonymity

The participants' real names were not used on the questionnaires and during report writing to ensure confidentiality.

4.6.4 Protection from harm

The research proposal was reviewed to ensure that it is ethical and participants will not be harmed. The participants were informed that they may not talk about issues that they were not comfortable with. Participants who showed distress and indicated a need for psychological support were referred to the Clinical psychologists at the participating hospitals' psychology units. Furthermore, the participants were informed that they were free to terminate the interview should they at any point feel uncomfortable to continue. Both the parents and the children were allowed time to talk about their experiences and feelings, which to some extent was beneficial to them.

4.6.5 Provision of care

Debriefing was done with the participants after data collection to monitor any unforeseen negative effects or misconceptions arising from the interaction. Participants who showed emotional stress and those who indicated psychological and social problems were referred for professional assistance e.g. clinical psychologists and Social Workers.

CHAPTER 5

PRESENTATION AND INTERPRETATION OF THE FINDINGS

5.1 INTRODUCTION

In this chapter, the results are presented and interpreted. The chapter is divided into two sections: quantitative results and qualitative results. The quantitative section covers the demographics, experience of grief by adolescents, association between demographics and adolescent grief experiences, effects of resilient factors on grief, the family resilient factors, and the moderation effect of the resilient factors on the grief experiences. The qualitative section has subsections that include the experiences of the adolescents as caregivers of the ailing parent, summary of the results and the conclusion. Testing of the hypotheses will also be done in this chapter.

5.2 DEMOGRAPHIC PROFILE OF THE STUDY PARTICIPANTS

The demographic factors of the participants (Both the sick parent and the child) are discussed in this section. The participants' gender, age, marital status, level of education, and employment history, are presented in the form of frequencies and percentages in table 1 below.

Table 1: Demographic profile of the sick parent

	HIV/AIDS infected parent.(n=95)		Cancer infected parent.(n=64)		p-values
	No	%	No	%	
Gender					
Male	19	20	5	8	0.033
Female	75	80	59	92	
Age					
30-39 years	31	32	16	25	0.013
40-49 years	44	44	34	53	
50+ years	9	14	14	22	
Unspecified	7	7	-	-	
Marital status					
Never married	33	36	26	41	0.767
Married	41	44	23	36	
Widowed	13	14	11	7	
Divorced	6	6	4	6	
Level of education					
No education	13	14	7	11	0.856
Primary education	12	13	11	17	
Secondary education	48	52	32	50	
Tertiary education	20	22	14	22	
Employment status					
Employed	27	34	30	47	0.123
Unemployed	52	66	34	53	

A total of 159 families participated in the study. Of these, 60% (95/159) were families with an HIV-infected parent and 40% (64/159) were families caring for a cancer diagnosed parent.

The results show that a high proportion of cancer infected parents (92%) were female as compared to HIV-infected parents (80%) – the results were statistically significant ($p < 0.05$). There were nineteen males who were infected with HIV/AIDS as compared to five males diagnosed with cancer.

The ages of the participants in the HIV/AIDS group ranged between 26 and 60 years ($M = 41.2$; $SD = 6.9$) and those in the cancer group ranged between 34 and 60 years ($M = 43.9$; $SD = 5.9$). The results indicate that four percent (4%) of the HIV/AIDS infected parents were in the twenty (20) to twenty-nine (29) years age group and there was no one from the cancer diagnosed group. Thirty-two percent (32%) of the HIV/AIDS diagnosed parents were in the thirty (30) to thirty-nine (39) years age group as compared to twenty-five percent (25%) from the cancer diagnosed group. This shows that a significant greater proportion of the HIV-infected parents were younger than 40 years as compared to the cancer infected parents (36% vs 25%, $p < 0.05$).

A high proportion of cancer diagnosed parents were above forty years as compared to the HIV/AIDS infected parents (75% vs 58%, $p < 0.05$).

Regarding the participants' marital status, thirty-six percent (36%) of the HIV/AIDS infected and forty-one percent (41%) of the cancer diagnosed parents reported that they were never married. Forty-four percent (44%) of the HIV/AIDS infected were married as opposed to thirty-six percent (36%) of the cancer diagnosed parents. Fourteen percent (14%) of the HIV/AIDS infected and seventeen percent (17%) of the cancer diagnosed parents indicated that they were divorced. Six percent (6%) from both groups were widowed. This shows that there was no statistical significant difference regarding the marital status ($p > 0.05$).

The results show that fourteen percent (14%) of the HIV/AIDS infected and eleven percent (11%) of the cancer diagnosed parents did not have formal education. Thirteen percent (13%) of the HIV/AIDS infected had primary education as opposed to seventeen percent (17%) from the cancer diagnosed parent. Fifty percent (50%) of parents from both groups

had secondary education and twenty-two percent (22%) had tertiary education. This indicates that there is no statistical significant difference regarding the level of education for the two groups ($p>0.05$).

Regarding employment status there was no significant statistical difference ($p>0.05$). Thirty-four percent of the HIV/AIDS infected and forty-seven (47) of the cancer diagnosed parents were unemployed, whereas sixty-six (66), fifty-three percent (53%) of the cancer diagnosed parents were employed.

Table 2: Demographic profile of the adolescent

	Adolescent caring for HIV infected parent (n=95)		Adolescent caring for Cancer infected parent (n=64)		p-values
	No	%	No	%	
<u>Gender</u>					
Male	38	40	32	50	0.213
Female	57	60	32	50	
<u>Age</u>					
11-14 years	30	32	15	24	0.718
15-17 years	38	40	27	43	
17-18 years	25	27	20	32	
18 years and above	1	1	1	2	
<u>Level of education</u>					
No education	3	3	1	2	0.920
Primary education	20	21	13	20	
High school	71	75	49	76	
Tertiary	1	1	1	2	
<u>Race</u>					
N. Sotho	94	100	62	96	0.075
Tsonga	-	-	2	4	
<u>Parent illness was</u>					0.316

Expected	26	28	17	27	
Unexpected	54	58	31	48	
Slow	7	8	12	19	
Sudden	6	6	4	6	

The demographic characteristics of the adolescents who cared for the sick parent are presented in table 2 above.

Adolescents involved in the caring of an HIV/AIDS infected parents consisted of forty percent (40%) males and sixty percent (60%) females; families involved with the caring of a cancer diagnosed parent consisted of fifty percent (50%) males and fifty percent (50%) females.

The age of the participants in both groups ranged from 11 to 18 years. Regarding adolescents caring for an HIV/AIDS diagnosed parent, thirty-two percent (32%) were within the 11 and 14 years group; forty percent (40%) were in the 15 and 17 years age group; twenty-seven percent (27%) were in the 17 and 18 years group, whereas one percent (1%) was in the 18 and above range. Those caring for cancer diagnosed parent were twenty-four percent (24%) in the 11 and 14 years range, forty-three percent (43%) 15 and 17 years range, thirty-two percent (32%) in the 17 and 18 years range and two (2%) percent was in the 18 and above years range. There is no statistical significance regarding the age between the two groups ($p>0.05$)

Regarding the level of education, the majority in both groups (HIV/AIDS and cancer) had high school education (75% and 76%), and very few had tertiary education (1% and 2%). There is however, no statistical significant difference regarding the level of education between the two groups ($p>0.05$).

The majority of the participants were N .Sotho speaking (100% and 96%). This could be due to the areas where the research was conducted, which has predominantly N. Sotho speaking individuals.

Among adolescents caring for an HIV/AIDS infected parent, twenty-eight percent (28%) indicate that the parent's illness was expected, fifty-eight percent (58%) said it was

unexpected, eight percent (8%) said it was slow, and six percent (6%) indicated that it was sudden. For the cancer affected group, twenty-seven percent (27%) said the parent's illness was expected, forty-eight percent (48%) indicated that it was unexpected, nineteen percent (19%) said it was slow, and six percent (6%) mentioned that it was sudden. There is no statistical significant difference with regard to parent illness between the two caregiver groups ($p>0.05$).

5.3 FINDINGS OF THE QUANTITATIVE PHASE

The research aimed at understanding the type of grief that the participants were presented with as well as the family qualities that were perceived as moderating the grief symptoms. This section will thus present the findings on the level and form of grief that the adolescents experienced as well as family factors that moderate the experience of grief.

The grief scale used in this study has two subscales: feelings during time of announcement of illness and the present feelings. This means that participants who showed high grief on both the past and present feeling would be categorised as having prolonged grief; low grief on both the past and present to be categorised as absence of grief; and those with delayed grief symptoms will have a low grief experience on past feeling and a high grief experience on present feeling; and acute grief will have a high grief on the past and a low grief on the present scale.

5.3.1 EXPERIENCE OF GRIEF BY ADOLESCENTS CARING FOR HIV OR CANCER PARENT

In this study it was found that the adolescents experienced grief from exposure to the family situations. The results show that for both family types, seventy-four percent (74%, $n=118$) experienced grief, whilst twenty-seven percent (27%, $n=43$) showed no experience of grief. It is also indicates in the results that in both families, twenty-one percent (21%, $n=34$) experienced acute grief, nineteen percent (19%, $n=30$) experienced delayed grief, whilst thirty-three percent (33%, $n=54$) experienced prolonged grief.

The two categories of families show different stages of experience of grief symptoms by the affected adolescents. Adolescents in the cancer category of families experienced prolonged (36%) and acute (23%) grief as compared to the HIV/AIDS group, whereas those in the

HIV/AIDS affected experienced more delayed grief (22%) as compared to their counterparts as shown in Table 3 below.

TABLE 3. The experience of grief by caregiver type

	Cancer caregiver	HIV/AIDS caregiver	Total
	N=64	N=95	N=159
	No (%)	No (%)	
Absence of grief	17 (27%)	25 (26%)	43 (27%)
Grief presentations			
Acute grief	15 (23%)	19 (20%)	34 (21%)
Delayed grief	9 (14%)	21 (22%)	30 (19%)
Prolonged	23 (36%)	31 (33%)	54 (33%)
Total grief	47 (73%)	71 (74%)	118 (74%)

5.3.2 FINDINGS ON THE PARENTAL DISCLOSURE OF THE STATUS OF THEIR DISEASES

The biographical questionnaire included a question whereby the participants were asked to indicate if the diagnosis was made and whether the parent disclosed the diagnosis to them. The following results indicate the extent to which parental disclosure of the status of their illness occurred in the families. There was a significant difference between the two categories of families in their extent of disclosure ($p < 0.05$) where cancer diagnosed parents disclosed more (75%) than the HIV/AIDS infected parents (55%). Regarding non-disclosure of the disease status, forty-five percent (45%) of the HIV/AIDS diagnosed parents did not disclose as opposed to twenty-five percent (25%) of the control group (see Table 4, below).

Table 4: Parental disclosure of disease status

	HIV/AIDS diagnosed N=95	Cancer diagnosed N=64	P Values P<0.05
Disclosed disease status	52(55%)	48 (75%)	0.0120
Non-disclosure of the disease status	43 (45%)	16 (25%)	
TOTALS	95 (100%)	64 (100%)	

5.3.3 RELATIONSHIP OF PARENTAL DISCLOSURE TO THE EXPERIENCE OF GRIEF

The study sought to find out if there is a relationship between experience of grief and parental disclosure. The findings indicate that there was no significant difference between disclosure and experience of grief symptoms for both categories. (see Table 5 below).

Table 5: Effect of parental disclosure of disease on adolescent's grief

	HIV/AIDS diagnosed (n=51 disclosed)	Cancer diagnosed (n=48 disclosed)	p-values
Lack of grief	11 (22%)	12 (25%)	0.686
Grief presentation	40 (78%)	36 (75%)	
TOTALS	51 (100%)	48 (100%)	

5.3.4 POTENTIAL FAMILY RESILIENCE FACTORS

The study sought to show if family qualities and resilience factors associated with the moderation of ambiguous loss and grief related symptoms among affected adolescents are unique and differ in relation to the family categories. The resilient factors are those factors that significantly correlated with the family attachment and Changeability Index (FACI) as per the ABCX Model. The results show that there are potential family resilience factors that differ according to the type of diagnosis. The factors will be discussed below.

5.3.4.1 Potential family resilience factors in adolescents caring for an HIV/AIDS diagnosed parent

The potential resilience factors among adolescents caring for an HIV/AIDS diagnosed parent were identified by highlighting factors correlating significantly with FACI. They include FCOPEs ($r=.476$ and $p<.000$), FHI ($r= .486$ and $p<.000$), and RFS ($r=.526$ and $p<.000$) as shown in Table 6, below. The three indices will be discussed in detail together with their significant sub-items hereunder.

Table 6: Pearson’s correlations for FACI-8 and other resilience factors in families caring for an HIV/AIDS diagnosed parent.

	FACI	
Resilient factors	R	P
FCOPES	.476	.000
FHI	.486	.000**
RFS	.526	.000*

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.4.2 Family Crisis Oriented Personal Evaluation Scale (F-COPES) factor

F-COPES (which is used to identify effective problem solving approaches and behaviours used by families in response to problems or difficulties) was found to have a significant correlation with FACI (which is used to measure the level of family adaptation). The significant correlation with FACI indicate that F-COPES is a potential resilient factor in families caring for an HIV/AIDS diagnosed parent.

Specific items that showed the correlation include item 2, 8, 10, 25 and 29. The items represent the following descriptions in the scale: item 2, “seeking encouragement and support from friends” ($r=.215$ and $p<.037$), item 8, “Receiving gifts and favours from neighbours” ($r=.215$ and $p<.000$), item 10, “asking neighbours for favours and assistance” ($p=.364$ and $r<.000$), item 25, “asking relatives how they feel about problems we face” ($p=.322$ and $r<.002$, and lastly item 29, “sharing problems with neighbours” ($r=.254$ and $p<.014$). (See Table 7 below).

TABLE 7: Pearson’s correlations for FACI and FCOPES in adolescents caring for an HIV/AIDS diagnosed parent.

FACI		
FCOPES)	r value	P value
2. Seeking encouragement and support from friends	.215	.037*
8. Receiving gifts and favours from neighbours (e.g. food, taking in mail, etc.)	.409	.000**
10. Asking neighbours for favours and assistance	.364	.000*
25. Asking relatives how they feel about problems we face	.322	.002**
29 Sharing problems with neighbours.	.254	.014*

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.4.3 Family Hardiness Index (FHI) factor

FHI which represents family hardiness was found to be significantly correlated with FACL making it a potential resilient factor as per the ABCX model in the families caring for an HIV/AIDS diagnosed parent ($r=.486$, $p<.000$).

Specific items that showed a correlation between the FACL-8 and FHI were items 2, 3, 8, 14 and 19. Each item represents the following description in the scale: item 2, “it is not wise to plan ahead and hope. Because things do not turn out anyway” ($r=.205$, $p<.047$); item 3, “our work efforts are not appreciated no matter how hard we try and work” ($r=.226$, $p<.028$); item 8, “it is better to stay at home than go out and do things with others” ($r=.256$, $p<.013$); item 14, “we tend to do things over and over...it is boring” ($r=.289$, $p<.005$); and item 19, “Most of the unhappy things that happen is due to bad luck” ($r=.226$, $p<.030$). (see Table 8).

Table 8: Pearson’s correlations for FACL and FHI in adolescents caring for an HIV/AIDS diagnosed parent(s)

FACL		
Family Hardiness Index	R value	P value
2. It is not wise to plan ahead and hope because things do not turn out anyway	.205	.047
3. Our work efforts are not appreciated no matter how hard we try and work	.226	.028
8. It is better to stay at home than go out and do things with others	.256	.013
14. We tend to do things over and over...it is boring	.289	.005
19. Most of the unhappy things that happen are due to bad luck	.226	.030

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.4.4 Relative and Friend Support Index (RFS)

RFS which represents Relative and Friend Support index was found to be significantly correlated to FACI making it a resilient factor in families caring for HIV/AIDS diagnosed parent ($r=0.526$, $p<0.000$).

Specific items indicating correlation between FACI and RFS in families caring for an HIV/AIDS infected parent were items 1, 2, 3, 4, 6 and 8. The items represent the following descriptions in the scale: item 1: “Sharing our difficulties with relatives” ($p=0.225$, $r<0.029$); item 2, “seeking advice from relatives” ($p=0.259$, $r<0.012$); item 3: “Doing things with relatives” ($p=0.344$, $r<0.001$), item 4: “seeking encouragement and support from friends” ($p=0.548$, $r<0.000$); item 6: “sharing concerns with close friends” ($p=0.220$, $r=0.033$); and lastly item 8: “asking relatives how they feel about the problems we have” ($p=0.290$, $r<0.005$). (see Table 9).

Table 9: Pearson’s correlations for FACI and RFS in adolescents caring for an HIV/AIDS diagnosed parent(s).

FACI		
RFS	R value	P value
1. Sharing our difficulties with relatives	0.225	0.029
2. Seeking advice from relatives	0.259	0.012
3. Doing things with relatives (get togethers etc.)	0.344	0.001
4. Seeking encouragement and support from friends	0.548	0.000
6. Sharing concerns with close friends	0.220	0.033
8. Asking relatives how they feel about the problems we have	0.290	0.005

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.5 POTENTIAL RESILIENT FACTORS AMONG ADOLESCENTS CARING FOR A CANCER DIAGNOSED PARENT

The resilience factors identified by factors significantly correlating with FACI as per the ABCX model, were F-COPE ($r=0.271$, $p<0.030$); FHI ($r=0.304$, $p<0.015$), and RFS ($r=0.406$, $p=0.001$) (see Table 10).

Table 10: Pearson’s correlations for FACI-8 and other resilient factors in families caring for a cancer diagnosed parent.

	FACI	
Resilient factors	R	P
FCOPES	0.271	0.030
FHI	0.304	0.015**
RFS	0.406	0.001*

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.5.1 Family Crisis Oriented Personal Evaluation Scale (F-COPES) factor

A significant correlation between F-COPES and FACI (in the cancer category) implies that F-COPES is one of the resilient factors in families caring for a cancer diagnosed parent. Item 5 of the F-COPES scale: “seeking advice from relatives”.

5.3.8.2 Family Hardiness Index (FHI) factor

Family hardiness significantly correlated with FACI and it is thus one of the resilient factors present in families caring for a cancer diagnosed parent(s). Specific items significantly correlating with FACI include items 2, 3 and 8. The items represent the following

descriptions in the scales: item 2: “it is not wise to plan ahead and hope because things do not turn out anyway” ($r=0.495$, $p<0.000$); item 3: “Our work efforts are not appreciated” ($r=0.428$, $p<0.000$); Item 8: “it is better to stay at home than to go out and do things with others” ($r=0.287$, $p<0.021$) (see Table 11 below).

Table 11: Pearson’s correlations for FACI and FHI in adolescents caring for a cancer diagnosed parent(s)

FACI		
Family Hardiness Index	R value	P value
2. It is not wise to plan ahead and hope because things do not turn out anyway	0.495	0.000
3. Our work efforts are not appreciated no matter how hard we try and work	0.428	0.000
8. It is better to stay at home than go out and do things with others	0.287	0.021

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.5.3 Relative and Friend Support index (RFS) factor

Relative and friend support index significantly correlated with FACI. This indicates that RFS is a potential resilient factor for families caring for a cancer diagnosed parent. Specific items that showed a significant correlation were items 1, 3, 4 and 8. The items represent the following descriptions in the scale: Item 2: “it is not wise to plan ahead and hope because things do not turn out anyway” ($r=0.495$, $p<0.000$); item 3: “our work efforts are not appreciated no matter how hard we try” ($r=0.428$, $p<0.000$); and lastly item 8: “It is better to stay at home than go out and do things with others” ($r=0.287$, $p<0.021$). (see Table 12).

Table 12: Pearson’s correlations for FACI and RFS in adolescents caring for a cancer diagnosed parent(s)

FACI		
RFS	R value	P value
1.Sharing our difficulties with relatives	0.320	0.010
3. Doing things with relatives (get togethers etc.)	0.462	0.000
4.Seeking encouragement and support from friends	0.339	0.007
8. Asking relatives how they feel about the problems we have	0.264	0.037

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

5.3.6 FINDINGS ON THE MODERATION EFFECT OF FAMILY RESILIENCE FACTORS ON THE EXPERIENCES OF GRIEF

The univariate analysis of data were used to determine the moderation effect of resilience factors on grief in families caring for an HIV/AIDS diagnosed member as compared to families caring for cancer diagnosed member.

5.3.6.1 Grief moderation effects for families caring for an HIV/AIDS diagnosed member.

5.3.6.1.1 Univariate regression analysis

The table below highlights the univariate regression analysis of results on the moderation effect of resilience factors on the experience of grief by families caring for an HIV/AIDS

diagnosed member as compared to the experience of grief by families caring for a cancer diagnosed member.

TABLE 13: The results of the univariate analysis (outcome=grief)

	Families caring for HIV/AIDS diagnosed member			Families caring for a cancer diagnosed member		
	B	SE	p-values	B	SE	p-values
FAC1-8	-0.05	0.077	0.534	0.05	0.058	0.407
FCOPES	-0.07	0.046	0.128	0.06	0.045	0.191
FHI	-0.13	0.082	0.116	0.12	0.072	0.106
RFS	-0.09	0.131	0.510	0.06	0.101	0.490

Univariate regression significant at 10-20 level

Four factors i.e. FACI-8, FCOPES, FHI, and RFS were found to moderate grief in families caring for an HIV/AIDS diagnosed member. This implies that grief in these families is moderated by the family's level of attachment to each other and the degree of flexibility, the family's problem solving approaches and behaviours, the family's hardiness, and relatives' and friends' support.

5.3.6.1.1.1 Moderating factors for grief by the univariate regression analysis

a. Family Attachment and changeability Index (FACI-8)

The univariate analysis results show that a negative relationship exist between FACI-8 and grief in families caring for a HIV/AIDS diagnosed member ($B=-0.05$; $p<0.50$). This indicates that as family attachment and changeability increase the grief in families caring for an HIV/AIDS diagnosed parent decreases. FACI-8 is thus a moderating factor for grief in families caring for HIV/AIDS diagnosed member.

b. Family Crisis Oriented Personal Evaluation Scale (F-COPES)

Family Crisis personal Evaluation (F-COPES) was found to have a negative relationship with grief in families caring for HIV/AIDS diagnosed member ($B=-0.07$; $p<0.13$). This indicates that as family crisis oriented evaluation increases, grief in families caring for an HIV/AIDS member decreases. F-COPES is therefore a moderating factor in families caring for an HIV/AIDS diagnosed member.

c. Family Hardiness index (FHI)

A negative relationship was observed for the FHI index and grief in families caring for an HIV/AIDS diagnosed member ($B=-0.13$; $p<0.116$). This indicates that if family hardiness increases, grief in families caring for an HIV/AIDS diagnosed member decreases. FHI is therefore a moderating factor in these families.

d. Relative and Friend Support Index (RFS)

The results of the univariate regression analysis further indicate that Relative and Friend Support is a moderating factor. There exists a negative relationship between RFS and grief ($B=-0.09$; $p>0.51$). This implies that if Relative and Friend Support increases, grief in families caring for an HIV/AIDS diagnosed member will decrease.

In summary, FOCI-8, FCOPEs, FHI, and RFS are the moderating factors in families caring for an HIV/AIDS diagnosed, member.

5.3.6.2 Grief moderation effects for families caring for a cancer diagnosed member

A positive relationship was observed between resilience factors FOCI-8, F-COPES, FHI, and RFS. The results show that when the resilience indices increase, grief also increases in families caring for a cancer diagnosed member.

5.3.6.2.1 Univariate regression analysis results

a. Family attachment and changeability Index (FACI-8)

The results of the univariate regression analysis indicates that FACI-8 has a positive relationship with grief ($B=0.05$; $p>0.407$). This means that when family attachment and changeability increase, grief in families caring for a cancer diagnosed member also increases.

b. Family Crisis Orientated Personal Evaluation Scale (F-COPES)

F-COPES was observed to have a positive relationship with grief in families caring for a cancer diagnosed member ($B=0.06$; $p<0.19$). The results indicate that when F-COPES increases, grief in families caring for cancer diagnosed member also increases.

c. Family Hardiness Index (FHI)

The results further show that FHI there exists a positive relationship between FHI and grief ($B= 0.12$; $p<0.11$). This indicates that when family hardiness increases, the experience of grief in families caring for a cancer diagnosed member also increases.

d. Relative and Friend Support index (RFS)

Relative and Friend Support was observed to have a positive relationship with grief in families caring for a cancer diagnosed members ($B=0.06$; $p>0.50$). The results indicate that as Relative and Friend Support increases, the experience of grief also increases.

In summary, FACI-8, F-COPES, FHI, and RFS were found to escalate grief in families caring for a member diagnosed with cancer.

5.3.7 SUMMARY OF THE QUANTITATIVE RESULTS

The statistics showed significant findings regarding the experiences of forms of grief among the HIV/AIDS affected adolescents and their control group (cancer group). The adolescents

in the cancer affected families experienced prolonged and acute grief as compared to their counterparts who experienced delayed grief. F-COPES, FHI, and RFS were found to be the potential resilience factors in both families. They, however, differed according to specific items. The results indicated that the FACL-8, F-COPES, FHI, and RFS had a moderating effect on the adolescents' experience of grief symptoms in the HIV/AIDS affected families as compared to their control group. The three indices seemed to escalate the level of grief in the cancer affected families.

5.4. QUALITATIVE RESULTS

The sections hereunder present the qualitative responses for the two groups. The participants were asked questions relating to their experiences following the parent's illness as well as the family qualities contributing to their resilience. The qualitative responses were aimed to elicit the feelings of ambiguous loss and those of grief and to further assess the qualities that aid in the moderation of stress in the affected families. Ambiguous loss is in this research understood to be the loss that happens before the actual death of an ailing member. Such loss is experienced when a family member, because of illness, is perceived as having died already. It also includes the loss of boundaries whereby a child is no longer able to assume childhood roles only, but due to the parent's illness assumes parental roles as a way to bridge the gap caused by the ailing parent. Grief is presented through negative feelings that include sadness, guilt, shame, anger and shock.

5.4.1 QUALITATIVE RESULTS FOR ADOLESCENTS CARING FOR AN HIV/AIDS DIAGNOSED PARENT

The themes that emerged from the questions asked are hereunder:

5.4.1.1 What was your first reaction towards the parent's illness?

The themes that emerged regarding the participants' response to the question on their first reaction towards their parent(s)' illness were feelings of grief as presented by sadness, loss, shock, shame and anger. These feelings were expressed in the statements from some participants as follows:

“I felt sad thinking that she was going to die”;

Others attributed their feelings of sadness to the fact that they didn't know that their disease is treatable:

“Firstly it hurts because I didn't know that the disease was manageable”.

Some participants attributed their feelings of sadness to lack of disclosure as indicated in these statements:

“I felt sad because she was admitted and we didn't know the cause”.

“I thought she was going to die because she also didn't have hope”

“Who is now going to pay for the societies?”

“I felt embarrassed really.”

5.4.1.2 Current feelings about the parent(s)' illness

The response of the participants on their current feelings about the parents' illness could be classified into two themes namely progressing towards acceptance, and acceptance. These are attested to by the statements that follow:

“I feel better because she is taking medication and the CD4 will rise”.

“I feel that my family and I will be healthy after the treatment”.

“I have accepted. Understand she is not the only one with the disease”.

“I am happy to know the type of illness”.

“I have accepted. She is healthy on treatment”.

5.4.1.3 What role are you playing now that your parent is ill?

The theme that emerged relating to the role that the participants are playing now that their parents are sick is role reversal. This was attested by the following statements:

“I make sure she takes food and medication well”.

“I do household chores”.

“I take her to hospital for treatment”.

“I take her to church for the rituals and prayers “.

5.4.1.4 How do you feel about the role that you are playing?

The responses of the participants regarding their feelings towards the role that they are playing include those of fulfillment, and another one is of being overburdened. The theme that emerged was that the participants were feeling ambivalent as there were feelings of fulfillment and those of being overburdened as attested to by the following statements:

"I feel good that I can help".

"I feel very confident; it shows that I am a grown-up".

"I am feeling good because I am supporting her".

"It is difficult because I do not go to school as usual".

"Not good because I sometimes do not know what to do".

"I am not feeling good because this is not my time to be a parent", and

"Not good. It is too much for me".

5.4.1.5 Have you experienced feelings of loss now that your parent is ill?

The response of the participants on the experience of feelings of loss could be structured into the feeling of anticipatory loss. This was attested by the following statements:

"Yes, she might die because she is very weak"

"Yes, people with this disease do not live long"

5.4.1.6. Was the diagnosis made, and then the issue discussed with you and how did it impact on you?

The response of the participants on whether the diagnosis was made and then the issue discussed with them and how it impacted on them. This situation could be arranged into three themes which are: acknowledgement, imposition, and negative impact. The themes are attested to by the statements that follow:

"Yes, she discussed the diagnosis with us".

"Yes, because she wanted me to remind her of the time for pills":

"Yes, but they didn't discuss anything with us, we don't know how to handle her"

"I only knew last month about the diagnosis".

"I just know that he must take medication and I must accompany him to the clinic every Tuesday".

"What were my parents thinking, how can they become so loose?"

"I was scared. Had pains in the chest".

"Guilty because she got it whilst producing me".

"Very sad, because I am also having the same diagnosis".

5.4.1.7 What do you regard as family quality that sustains you during times of hardships?

The response of the participants on the family qualities that sustain them during times of hardship can be divided into two themes, i.e. family and friends' support, and spirituality.

This is attested to by the statements:

"We consult with the nurses and the Doctors at the clinic".

"We eat healthy as prescribed by the dietician".

"We consult with the social workers".

"We talk to each other about our challenges"

"We laugh together".

"We support each other".

"As family we stick together".

The other group indicated that they seek spiritual assistance during times of hardship. This is attested by the following:

"We pray".

"We consult with the pastors at church".

"God has a purpose for this".

5.4.1.8 SUMMARY

The responses given suggest that the participants anticipated the death of their parents when they got sick, hence they had feelings of grief and that of loss. The participants further indicated that they had taken over their parents' responsibilities since they could no longer undertake those parental roles fully anymore. Even though their parents are still alive, the

weakening bodies make it difficult for them to carry out some of their duties. Feelings of ambivalence towards the role played were also eminent. Family support, professional support, and spirituality were reported as the families' source of strength in dealing with the challenges. This is in line with the expression of the situation as an experience of ambiguous loss defined by Boss (2006).

5.4.2 QUALITATIVE RESULTS FOR ADOLESCENTS CARING FOR A CANCER DIAGNOSED PARENT

5.4.2.1. What was your first reaction towards the parent's illness?

The themes that emerged regarding the participants' response to the question on their first reaction towards their parent(s)' illness were feelings of grief as presented by sadness and loss. These are attested to by the following statements:

"I felt sad because we are too young to lose a parent".

"I didn't enjoy myself anymore and was feeling pain."

Others attributed their feelings of sadness to the fact that they did not know what caused the disease:

"I felt pain as we didn't know the cause":

"I thought we were going to lose her":

"Cancer kills, I thought she will die".

"We didn't have hope, she was in severe pain".

5.4.2.2 Current feelings about the parent(s)' illness

The response of the participants on their current feelings about the parents' illness could be classified into two themes namely, sadness and progressing towards acceptance, as attested to by the followings:

"I am still irritable. Happy for a few minutes".

"It is still difficult, not sure whether he will make it or not".

Some mentioned reasons for their feelings of sadness for example:

"I am not happy. Not good to see her lying in that bed. She seems in severe pain".

"I feel better because she is taking medication and is recovering well".

"I feel happy because mom is going to get medication and is going to be well".

"The Doctor said she will make it. I feel happy."

5.4.2.3 What role are you playing now that your parent is ill?

The participants' response to the role they are playing given that their parents are sick is categorised as role reversal. This was expressed in the following statements by some of the participants:

"I make sure she takes food and medication well".

"I do household chores".

"I bathe her".

"I take her to church for the rituals and prayers."

"I accompany her to hospital for treatment".

5.4.2.4 How do you feel about the role that you are playing?

The responses of the participants regarding their feelings towards the role that they are playing include that of fulfillment, and being overburdened. These could be categorised as ambivalence as attested to by the participants in the following statements:

"I feel good that I can help".

"I feel very confident; it shows that I am a grown-up".

"Difficult because I do not know how to handle her".

"Not good. I do not feel comfortable to bathe her because I am a boy".

"I am not feeling good because this is not my time to be a parent", and

"Not good. It is too much for me".

5.4.2.5 Do you experience feelings of loss now that your parent is ill?

The response of the participants on the experience of feelings of loss could be structured into two themes. These include the experience of the feelings of anticipatory loss and lack of symptoms. This was attested to by the following statements:

“Yes, because she complains about pains every day”.

“Yes, because my grandmother also died “.

“Yes, cancer kills”.

“No, she has improved on medication”.

“She is no longer complaining of pain”

“She has started with chemotherapy, and will be fine”

5.4.2.6 Was the diagnosis made or discussed, and how did it impact on you?

The participants’ response on whether the diagnosis was made or discussed, and how it impacted on them could be arranged into three themes which are: acknowledgement, imposition, and negative impact. Although the participants acknowledged that the diagnosis was discussed with them, it looks like an imposition as attested by the following responses:

“Yes. I was just told to accompany her to church for the week for rituals not considering that I must go to school too. ‘

“I was just told she has cancer I must take care of my siblings. What does this mean?”

The diagnosis had a negative impact on them as they reported feelings of sadness and fear. This is attested to by the following:

“I was scared. Had pains on the chest”.

“It is sad, cancer kills”.

“I do not eat and sleep well anymore”.

5.4.2.7 What do you regard as family qualities that sustain you during times of hardships?

The response of the participants on the family qualities that sustain them during times of hardship can be divided into two themes i.e. family and friend support, and spirituality.

This is attested to by the following statements:

“We consult with the nurses and the Doctors at the clinic/ hospital”.

“We talk to each other about our challenges”.

“We play and laugh together”.

“We support each other”.

“As family we stick together”.

“In our family we talk about our problems”.

“Communication is the best”.

“We pray”.

“We consult with the pastors at church”.

“We know it is God’s will”.

5.4.3 SUMMARY OF THE QUALITATIVE RESULTS

The table below provides the summary of the identified themes and their prevalence within the sample. Item C1 refers to the participants’ first reaction to the illness, C2 refers to their current feelings, C3 the role that they are playing, C4 how they felt about the role they are playing, C5 whether they experienced feelings of loss or not, C6 whether a diagnosis was made or not, whether it was discussed, its impact on them, and C9 is the family qualities that have a moderating effect.

Table 14: Summary of the average frequencies with which themes were mentioned by participants

Item	Theme	Families caring for HIV/AIDS diagnosed parent (N=95)		Families caring for parent diagnosed with cancer (N=64)	
		No	%	No	%
C1	Feelings of sadness	64	70	41	64
	Feelings of loss	11	12	21	33
	Feelings of shock	5	5	-	-
	Feelings of shame	4	4	-	-
	Feelings of anger	3	3	-	-
C2	Progression towards acceptance	17	18	45	70
	Acceptance	55	17	-	-
C3	Role reversal	73	38	19	31
	Taking her to hospital/church	17	18	13	20
C4	Positive feeling	70	74	47	73
	Negative feeling	7	7	11	17
C5	Grief symptoms	53	56	48	75
	Lack of symptoms	33	35	16	25
C6	Acknowledgement of diagnosis made	63	66	34	55
	Imposition	31	33	26	40
	Negative impact	58	61	39	61
C7	Family support	16	17	32	50
	Spiritual support	6	6	28	44
	Professional support	13	14	4	6
	Spirituality	6	6	11	17
	Communication	-	-	4	4

To summarise the results of the qualitative data, it can be said that the participants in both categories experienced differing feelings during the stages of their parents' illness. The overall feeling experienced is that of grief as presented in the form of sadness, hurt, loss and anger which were reported as the initial reaction to the illness. These feelings were experienced within anticipatory loss of their parents as well as an experience of feelings of loss of their childhood as a consequence of unavoidable role reversal due to potential incapacity imposed by illness. The new roles included reminding parents to take treatment, doing household chores, and organising transportation of parents to hospital or church for treatment.

Such role reversal induced mixed feelings, as they at times felt good to be able to assist but feeling equally being overburdened by it. With regard to the diagnosis the participants felt that although there were some discussions around it they also felt there was some imposition as their views were not considered. Family strengths that were identified include family and friends support, as well as spirituality which was reported more by the cancer affected group as compared to the HIV/AIDS group.

5.4.4 CONCLUSION

It can be concluded that the two groups experienced ambiguous loss that is in the form of anticipatory loss and boundary ambiguity during the illness of the parents. Family qualities moderating the symptoms of grief e.g. sadness, were found to be family support, spirituality, communication and professional support. Family support, spirituality, and communication were more prevalent in the cancer group than the HIV/AIDS group. The shame experienced by the HIV/AIDS affected group could minimise the use of family for support. The availability of antiretroviral treatment seems to buffer the experience of sadness and to bring hope to the adolescents.

5.5 INTEGRATION OF THE QUANTITATIVE RESULTS WITH THE QUALITATIVE RESULTS

This section will present the integration of the results as well as the test of the hypotheses in the study.

5.5.1 Results on the experiences of ambiguous loss in families that have members with HIV/AIDS or cancer

The research sought to identify the experiences of ambiguous loss in families with a parental diagnosis of HIV/AIDS or cancer. The qualitative method was used whereby semi-structured questions were asked and themes were identified. Ambiguous loss is in this research understood to be the loss that happens before the actual death of a member. It is experienced when a family member, because of illness, is perceived as being dead. It also includes the loss of boundaries whereby a child is no longer able to assume only the

childhood roles, but due to the parent's illness assumes a parental role as a way to bridge the gap caused by the parent's illness.

The qualitative results show that the participants (both HIV/AIDS affected and cancer affected) assumed a caregiver role when their parents became ill. The role played ranged from reminding parents of time for medication (common in the HIV/AIDS group) and taking parents to hospital or church (common in the cancer group). This implies that they lost their role of being children and assumed a parental role, although both the two groups were involved in ensuring that the parent took medication. The HIV/AIDS group were mostly concerned about the parent not missing time for medication; the cancer group was just concerned with the fact that the parent(s) takes medication. The cancer group, unlike the HIV/AIDS group, was more involved in taking the parent to hospital or church for rituals. The two groups reported feelings of loss following the illness of the parent, but the feelings were reported by the majority of the cancer group.

Hypothesis 1 that the experience of ambiguous loss in families that have HIV/AIDS diagnosed parent(s) will differ from those in families that have parent(s) diagnosed with other conditions is thus not supported as both groups experienced ambiguous loss in the form of boundary ambiguity and anticipatory loss.

5.5.2 Results on the experience of a form of grief by participants

The quantitative results showed that most of the participants experienced grief. However, adolescents who cared for cancer parents tended to experience acute and prolonged grief, while those who cared for the HIV/AIDS parent experienced delayed grief. The results further indicated that the HIV/AIDS caregivers experienced more negative symptoms than the adolescents in the cancer caregiver category.

The qualitative results on the other hand indicated that both groups experienced feelings of sadness, loss, anger and acceptance. These feelings signify the stages of grief that one goes through as indicated by Elizabeth Kubler Ross' stages of grief (Kubler-Ross, 1969). The other theme that emerged was that of anticipating the loss of the parent, which could be attributed to anticipatory loss. For the HIV/AIDS group, more sadness was experienced in the initial stages and reported to subside as the parent got better on medication. The fact

that there are more other people taking treatment at the ARV clinics, was also found to help in minimising the symptoms of grief.

For the qualitative and quantitative data analysis, forms of grief were reported in both cases. The cancer affected group had prolonged grief as the feelings of sadness were still present during the interviews, unlike in the HIV/AIDS group, whose feelings were reported to subside with the treatment effect on the ailing parents.

Hypothesis 2 that HIV/AIDS affected adolescents experience forms of grief related symptoms during their parents' illness that will differ from those affected by other conditions is supported in that HIV/AIDS affected group experienced delayed grief as opposed to acute and prolonged grief experienced by adolescents affected by parental cancer diagnosis.

5.5.3 Results on the experience of grief according to the adolescent's demographics

The results of the quantitative data showed no significant difference in the adolescents' experience of grief by demographics. Hypothesis 3 that affected adolescents experience ambiguous loss and grief reactions whilst caring for the ailing parent, this differs according to demographic factors and is thus not supported.

5.5.4. Results on the influence of parental disclosure/ non-disclosure on the experience of ambiguous loss and grief related symptoms

According to the qualitative results, a significant lower proportion of the HIV/AIDS infected parents disclosed their disease status to their families. This is in line with the results of the qualitative data, whereby a lower number of parents reportedly did not disclose their status to their families. There is, however, no significant difference between parental disclosures of disease on adolescents' grief scales. This implies that the parental disclosure of disease did not have an effect on the adolescents' grieving. Hypothesis 4 is thus not supported.

5.5.5. Results on the potential family resilient factors

Different resilient factors were reported by both the HIV/AIDS and the cancer affected groups in the quantitative data analysis. Although the three resilient factors were present in the two groups, they differed in the specific items. Regarding the use of F-COPES, HIV/AIDS affected groups used mainly seeking encouragement and support from friends, receiving gifts and favours from neighbours, asking neighbours for assistance, asking relatives how they felt, and sharing problems with neighbours, whereas the cancer group sought advice from relatives. This is in contradiction to those of the qualitative data, where the themes that emerged regarding the family resilience factors were family support and spirituality for the cancer affected families, and for the HIV/AIDS group support was sought from professionals.

The results of the quantitative and qualitative data suggest that the potential family resilience factors in the HIV/AIDS are unique and differ from those affected by cancer. Hypothesis 6 that family qualities and resilience factors associated with the moderation of ambiguous loss and grief related symptoms among affected adolescents in HIV/AIDS affected families are unique and differ from those factors that sustain families affected by other conditions is thus supported.

5.6 CONCLUSION

According to the results reported in this chapter, 159 adolescents participated in the study. Ninety-five cared for HIV/AIDS diagnosed parents, and 64 cared for cancer affected parents. The two groups experienced differing grief symptoms in terms of duration (acute, prolonged, and delayed). The HIV/AIDS affected group experienced delayed grief whereas the cancer affected group experienced acute and prolonged grief. The adolescents' demographics and parental disclosure of the disease did not have an effect on their experience of grief in line with the ABCX model. The correlation of factors such as F-COPES, RFS, and FHI with FACI yielded resilience factors in the families highlighting family qualities that may help families bounce back during the experience of caregiver stress. Different resilience factors were identified for the different groups with differences

highlighted further on the specific items within the resilience factors. The next chapter will present a detailed discussion of these results.

CHAPTER 6

DISCUSSION

6.1 INTRODUCTION

This study aimed at determining the experience of ambiguous loss and grief in adolescents affected by parental diagnosis of HIV/AIDS and the identification of potential family qualities and resilient factors that moderate the grieving symptoms. The main objective was to find and explore if adolescents experience grief during their parent(s)' illness and whether there are qualities within the family that buffer the experience of grief.

The study further explored whether there were any demographic differences in the experience of ambiguous loss and grief related symptoms by the affected adolescents. The forms of grief related symptoms that the adolescents in the HIV/AIDS affected families experience were further compared with those of families affected by cancer.

The study also looked at whether the resilience factors present in the HIV/AIDS affected families are unique and differ from those in families affected by cancer. During the discussions in this chapter, the following descriptions will apply for the highlighted resilience factors: FACI-8 referred to as an indicator of "family attachment and changeability", F-COPES referred to as an indicator of "internal and external family coping patterns", RFS referred to as "relative and family support" and FHI referred to as "family hardiness". Furthermore, adolescents caring for a parent with HIV/AIDS diagnosis will be referred to as "adolescents or families affected by HIV/AIDS", and those caring for a parent with a cancer diagnosis will be referred to as "adolescents/ families affected by cancer".

The results are discussed in relation to aims and objectives of this study and are described within the McCubbin Resilience model of stress, adjustment and adaptation.

6.2 THE DEMOGRAPHICS OF SICK PARENTS AND AFFECTED ADOLESCENTS WITHIN THE FAMILIES IN THIS STUDY

The demographic profile of the sick parent for both the HIV/AIDS and cancer diagnosed parents as well as those of adolescents in the two groups were looked into in this study. The specific outcomes are discussed below.

6.2.1 Gender of the sick family member

There was a significant difference in the gender of the HIV/AIDS infected group and those of the cancer group. There were more females in the cancer group as compared to the HIV/AIDS group. This could be due to the fact that the majority of females are diagnosed with breast or cervical cancer. Cancer has also been regarded as an opportunistic condition as most HIV/AIDS infected individuals also had a cancer diagnosis. The second reason is that in cases where both the diagnoses were made for a patient, family members and the patient preferred to disclose the cancer diagnosis in contrast to the HIV/AIDS due to the stigma that it carries.

6.2.2. Age of the sick family member

The study noted a significant difference regarding the gender of the sick parent in both groups. A high proportion of HIV/AIDS infected parents were younger than forty years as compared to their counterparts. One mode of HIV/AIDS contraction is through sexual activity. The majority of women younger than forty years are still sexually active and thus the difference in the ages. Even though the difference was not significant, the majority of the parents in this study are married and that put them at a high risk for HIV/AIDS infections. In the African culture, husbands are considered superior to their wives, as such it becomes difficult for a wife to make decisions regarding sex and use of protection. Most husbands do not stick to one partner.

6.2.3 Level of education

There was no significant difference regarding the level of education in the HIV/AIDS and the cancer group. The data were collected in the public hospitals and clinics for both groups. The majority of professionals received their healthcare services in private healthcare facilities which could explain the lack of difference in the level of education for the two groups.

This would also explain the lack of difference in the employment status of the two groups in this research.

6.3 DEMOGRAPHIC PROFILE OF THE ADOLESCENT

The demographic profile of the adolescents in this study was not significantly different in respect of age, gender, and level of education, race, and parents' illness. The results could have been accounted for by the fact that they were all at the same developmental stage, and also that currently the caregiving role is performed by both males and females. Most boys are seen to be assuming the same responsibilities/ roles as the girl children. The sick parents in this study were the ones who gave the researcher the name of an adolescent child who seemed to be playing the role of a caregiver.

6.4 EXPERIENCES OF AMBIGUOUS LOSS BY ADOLESCENTS

The results showed that both groups experienced ambiguous loss as they had to play a caregiver role not only to their sick parent, but also to their siblings. A few reported having stopped attending school as parents needed intensive care and they were the only source of support. The results are supported by the report by Roos (2002) that chronic sorrow refers to the ongoing feelings of sadness due to chronic or permanent loss. Unlike normal grief that is precipitated by the death of a loved one, chronic sorrow is brought about by the permanent loss of a significant relationship (Eakes, Burke & Hainsworth, 1998). Boss (2006) also indicates that children experience ambiguous loss when they cannot bring their perceptions of who they are into line with personal, familial, and community expectations.

The difference in the experiences of ambiguous loss in the two groups could be better explained by the attachment theory, which states that grief is a deficit reaction to separation from the attachment figure (Bowlby, 1973, 1980).

6.5 EXPERIENCES OF GRIEF BY ADOLESCENTS CARING FOR HIV/AIDS OR CANCER PARENT

The results in this study show that the adolescents experience different forms of grief during their caring of parents. Adolescents who cared for HIV/AIDS diagnosed parents experienced delayed grief, whereas those caring for cancer diagnosed parent experienced acute and prolonged grief.

The results on the experience of acute grief in the families with a cancer diagnosed member are in line with those of McCubbin *et al.* (2002), in families caring for a child with cancer. They indicate that parents describe feelings of shock, disbelief, unreality, and fear at hearing the diagnosis and are overwhelmed by a lot of information given by the healthcare providers regarding the type of cancer and treatment that the child should receive.

The prolonged grief was also found in families caring for patients diagnosed with dementia (Malak *et al.*, 2016). The results are in line with those obtained by Elvira de la Morena & Cruzado (2013), and O'Connor, Wellisch, Stanton, Olmstead & Irwin (2012) who found that caregivers of people with disorders of consciousness e.g. Vegetative State (VS) and Minimally Conscious State (MCS) met the criteria for the diagnosis of prolonged grief disorder (PGD). The prevalence of PGD is higher (45%) than those reported by Chiambretto *et al.*'s (35.6%), Guarnerio *et al.*'s (15%) or by Leonarri *et al.*'s (27.6%) research. It is, however, lower than that of Elvira de la Morena & Cruzado (60%).

The results on the experience of delayed grief in families affected by HIV/AIDS were not in line with those reported by Chi *et al.* (2013), and Pelton & Forehand (2005), who reported that some children affected by HIV/AIDS do not present with significant or elevated levels of mental health problems. However, Shorter & Stayt (2010) and Malison (2013) reported that nurses working with HIV/AIDS patients experienced prolonged grief due the trauma of watching their patients deteriorating.

The explanation of difference in the experiences of PGD in the above groups could be the age. The mean age for the caregivers in this group was 15 years, whereas it was higher in the other groups of Chiambretto *et al.*'s (28-82 years), and Guarnerio *et al.*'s (31-84 years) or of Leonardi *et al.*'s (52.3 years). Studies have shown that younger people have a higher risk of PGD than older ones. Younger people have not developed the necessary cognitive and emotional means of dealing with challenges, whereas older people have due to their level of maturity developed the necessary cognitive and emotional skills to deal with challenges including acceptance of grief. According to Chiambretto *et al.* (2010), a longer duration of the vegetative state is associated with a lower prevalence of PGD. Parents in this study had been ill for less than 24 months, whereas the participants in the other studies had been ill for about three years. This could also explain the difference in the experience of prolonged grief between the HIV/AIDS and the cancer group, as the cancer parents' years of illness were less than those of the HIV/AIDS group.

Research has also shown that caregivers of patients with DOC present with high levels of stress, which incurs a risk of developing prolonged grief disorder (Guarnerio *et al.*, 2012; Chiambretto *et al.*, 2010). Caring for a cancer patient could be more distressing, thus the development of a higher PGD in the cancer caregivers than the HIV/AIDS caregivers. The experience of prolonged grief is further explained by the attachment style. Kissane *et al.* (2012) and Delespau *et al.* (2013) found that bereaved individuals with anxious attachment are likely to experience chronic grief, which is characterised by intense anxiety, anger and sorrow, yearning for loss, failure to accept the loss, and difficulties in establishing a new life structure.

This could explain the different types of grief reported in this study. Cancer caregivers, due to its life threatening nature or its being not curable, leads to intense grieving. HIV/AIDS is currently manageable as it was reported by the participants in the qualitative study, who indicated that they felt better because the parent was not the only one taking the medication. The use of antiretroviral treatment has led to a paradigm shift in which HIV/AIDS is currently a chronic illness. This could explain the reason why the HIV/AIDS affected experience delayed grief. It seems after a diagnosis is made, caregivers start to grieve when they realise that the parent does not recover and had to live with the condition for the rest of their lives. Some of the participants in the HIV/AIDS group were also infected

and receiving the antiretroviral treatment. This could have also buffered the symptoms as they realised that they themselves survived. The grief experiences, however, differed according to the diagnosis of the parent.

6.6 EXPERIENCE OF GRIEF BY DEMOGRAPHICS

There was no significant difference in the experience of grief according to demographics. This could be due to the fact that the participants were all adolescents, in the same developmental stage. The results are not in line with those found by Thurston *et al.* (2008), that the secrecy with HIV/AIDS makes coping for children in particular a great challenge, as they are at increased risk for unresolved or complicated grief because of their developmental vulnerability (intellectual immaturity and emotional dependency). The other reason that could have led to this is that culturally there seems to have been a shift in terms of roles per gender. More males are now seen to be involved in taking care of babies, cooking, etc. roles which were previously regarded as females roles.

Traditionally, extended families were highly considered. This was due to poor socio-economic status, unlike now where most people are economically better off and therefore there is no need to stay with aunts, uncles, cousins, grandparents, etc.

Age was found not to contribute towards the development of depression in families caring for a relative with dementia. Some studies found that adult daughters had a greater caregiver burden scores as compared to distant relatives (Prosser, Lamarand, Gebremariam & Wittenberg, 2014)

The calculation of stressor pile-ups as per the Resilience model of stress and adaptability has varied between researchers, with others viewing it as the number of stressful life-events, whereas others used it as perceived caregiving burden or child characteristics (age, adaptive skills, challenging behaviour, level of disability etc.) (Frishman *et al.*, 2017). These findings are not in line with what was found in this study.

The research was also conducted in the Capricorn District where the main language is Sepedi, hence no difference was observed

6.7 DISCLOSURE

The results in this study showed that a significant lower number of HIV/AIDS infected parents disclosed their status to their families compared to the cancer group. This could have contributed to the experience of delayed grief in the HIV/AIDS caregivers. It is also difficult for the HIV/AIDS infected to disclose their status due to fear of being rejected unlike individuals with cancer. For the cancer group, those who did not disclose the diagnosis to their families were because they wanted to protect them against being rejected. There was, however, no significant difference between parental disclosure of disease and adolescents' grief.

The results are not in line with the report by Boss (2002, 2006) and Abramson (1990), that for the HIV/AIDS infected, affected family members are in a state of perpetually trying to make sense of what in their eyes is a progressive deterioration of a sick family member; this gets worse if there has not been any disclosure, especially for the child caregivers (Boss, 2002, 2006; Abramson, 1990).

6.8 POTENTIAL RESILIENCE FACTORS IN FAMILIES AFFECTED BY HIV/AIDS OR CANCER

Potential family resilience factors are those factors that correlate significantly with the family adaptability and changeability scale, the FACI. The resilience factors found in families affected by HIV/AIDS were similar to those in families affected by cancer. They are FCOPES, FHI, and RFS, as discussed and illustrated in Figure 3, below.

6.8.1 Family problem solving methods (F-COPES)

The significant correlation of F-COPES with FACI indicates that there are problem solving approaches and behaviours that HIV/AIDS affected families and their counterparts (those affected by cancer) use in response to the problems or difficulties. The approaches include: seeking encouragement and support from friends, receiving gifts and favours from neighbours, asking neighbours for favours and assistance, asking relatives how they feel about the problems they are facing, and lastly they share their problems with neighbours.

The methods, however, differed from those used in families affected by cancer as they seek advice from relatives when they are confronted with problems.

The approach used in these families is seeking support outside the family but from friends and neighbours. The results are in line with a report by Walsh (2011) who indicates that prolonged adversity or crisis might shatter the family's cohesion, resulting in members not trusting each other for support. HIV/AIDS is currently classified as a chronic condition due to the antiretroviral treatment patients receive, unlike cancer which depends on the stage in which it was diagnosed. The use of lay counsellors for support in HIV/AIDS can also lead to the affected members not relying on family for support because of the stigma that comes with such a diagnosis. Members diagnosed with HIV/AIDS also feel more comfortable to share their status with people outside the family circle than inside. This was also confirmed by the insignificant greater number of disclosures in the HIV/AIDS families than the cancer families in this study.

6.8.2 Family hardiness as a resilience factor (FHI)

Family hardiness as a potential resilient factor in both the HIV/AIDS and cancer affected families implies that the two families have internal strengths to deal with adversity. It shows how well the family believes they can handle stress in their lives irrespective of whether people support them or not. They also seem to have an internal locus of control as they believe that things happen to them due to bad luck.

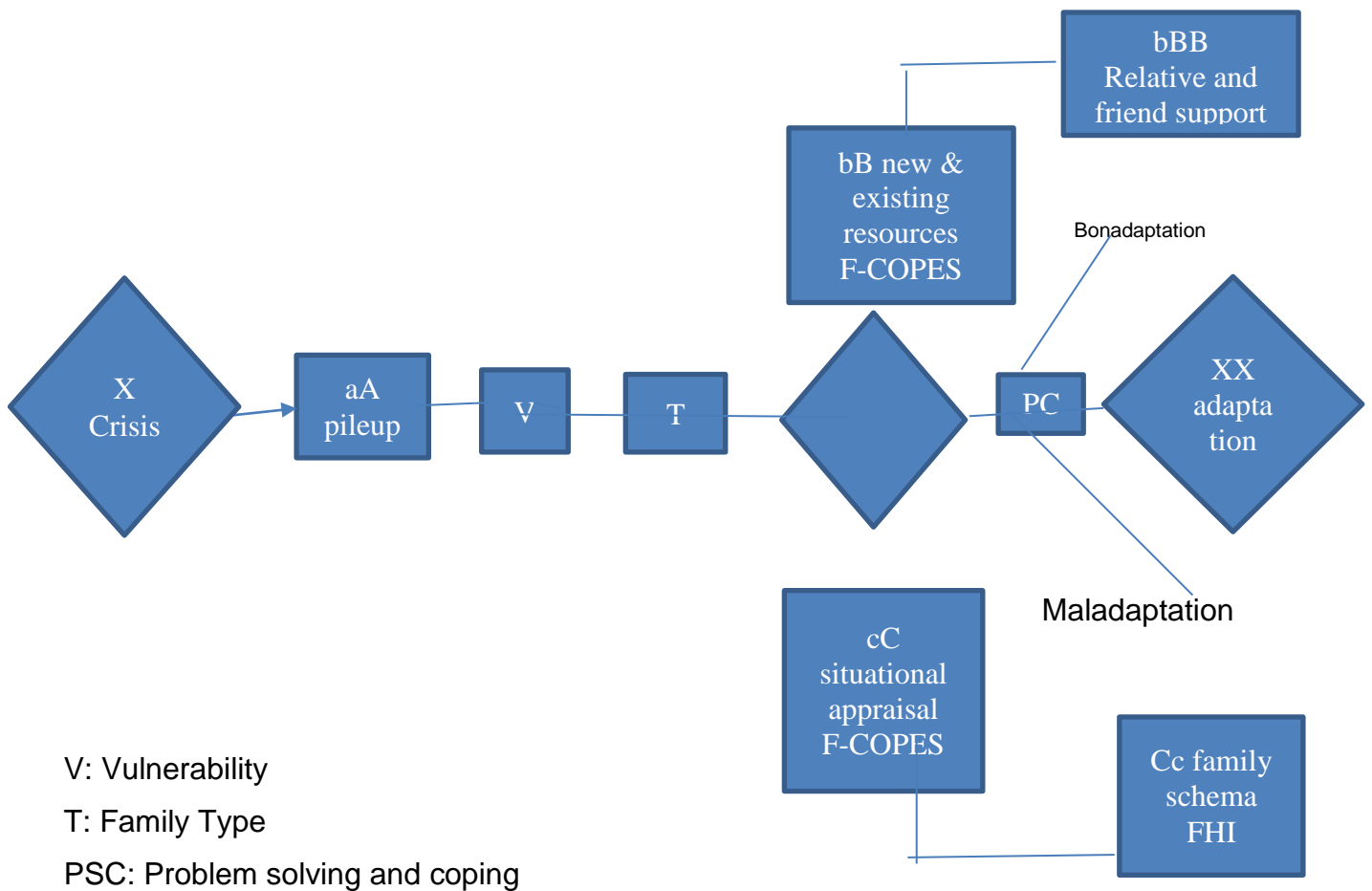
6.8.3 Relative and friend support (RFS)

Other resilience factors found in this study is relative and friend support. The HIV/AIDS affected families seem to have the potential to share, seek advice, and do things with relatives. They also could cope by seeking encouragement and support and sharing concerns with friends. The results are in line with those by Mashego & Taruvinga (2014), who found that in the impact of divorce in adolescents was moderated by family support for its members and the rate of togetherness and doing things together as a unit. The results are further explained by the double ABCX model that postulate that existing and new resources are the family's capabilities to meet the demands and needs. Examples of

resources include individual characteristics, and family and community characteristics (McCubbin & Patterson, 1983; McCubbin & McCubbin, 1996).

A diagrammatic representation of the potential resilient factors in the HIV/AIDS and cancer affected families per the existing Resilience model of stress, adjustment and adaptation is shown in figure 3 below. The new resources are the F-COPES, RFS, and FHI which seem to help families adapt when faced with a stressor of a parental diagnosis of HIV/AIDS or cancer.

Figure 3 below represents the insertion of resilience factors on McCubbin Resiliency model of stress, adjustment and adaptation, for families affected by HIV/AIDS or cancer



6.9 MODERATING EFFECT OF THE RESILIENCE FACTORS ON GRIEF ACCORDING TO FAMILY TYPOLOGY

The study sought to identify the unique family resilience factors that moderate the experience of grief in the families affected by HIV/AIDS as well as those families affected by their counterparts. The regression analysis results showed that F-COPES, FHI, and RFS have a negative relationship with grief in adolescents affected by HIV/AIDS. This implies that when the three indices mentioned increase, grief in families affected by HIV/AIDS decreases. There was a positive relationship between the resilience indices and grief in cancer affected families, which means that the resilience factors escalated the experience of grief in the cancer affected families.

6.9.1 Relative and friend support as a moderator of grief (RFS)

The results show that social support moderate the experience of grief in families affected by HIV/AIDS. This is in line with the research findings that indicate that children whose families are caring, have a more positive health than those from uncaring families (Betancourt *et al.*, 2011; Kapp & Brown, 2013). It is further supported by Mashego and Taruvinga (2014), who found the importance of family support in moderating the impact of divorce in teenagers from divorced families. The results found by Setwaba (2015) also indicate that the support of friends and family for HIV/AIDS affected families was a buffer to stress.

The health-care system's supply of antiretroviral treatment, counselling provided by lay counsellors to HIV/AIDS diagnosed patient were in this study found to play a great role in helping the family adapt to the stressor of caring for the ill parent. The ARV clinics also serve as adaptive resources as most participants indicated that they realised that the family member was not the only one with the disease and that gave them hope. It also buffers the issue of stigma as the disease is spoken of freely in such institutions. Seeing others looking healthy despite the infection gives family members hope. This leads to the caregivers seeing themselves as not alone, having open discussions about the diagnosis, and utilising the support of friends and healthcare providers to minimise the symptoms of grief.

According to STATS SA (2017), life expectancy in South Africa has increased to 64 years in 2017 from 53 years in 2006. The use of antiretroviral treatment programme can also be regarded as a moderating factor for grief experience as reported by participants in this study. HIV/AIDS is thus perceived as a chronic illness. This helps in buffering the experience of grief.

These results are not consistent with those of Strivens & Craig (2014) and Malak *et al.* (2016) who found that although dementia is a chronic illness, the support that the family members receive does not buffer the symptoms of depression. This was attributed to the activities that the caregivers of patients with dementia engaged in.

Social support from friends and family was in this study not found to be the moderator of grief in families affected by cancer. This could be explained by the fact that although the resilience factors are available in families, it is the responsibility of family members to seek the available support and use it (McCubbin *et al.*, 2002; Sherman *et al.*, 2014). The results, however, align with those of Velez *et al.* (2013), who state that the physical pain that the cancer patient has, and having little control over those symptoms, increases the level of grief and suffering in families affected by cancer. Families often avoid talking about painful or threatening issues like a serious illness, with the intent to protect members from pain. The anxiety about the unspeakable can result in serious problems, especially in children (Walsh, 2011). This could be the case in cancer affected families where pain is avoided and in turn, the children suffer the consequences.

6.9.2 Family hardiness (FHI) as the moderating factor

Family hardiness was found to diffuse the level of grief in the HIV/AIDS affected families. This implies that the family relies on its internal strength to adapt to the stress of caring for a member that is diagnosed with HIV/AIDS. The results are in line with the research findings by Blachard (1997), in which family hardiness was the strength that facilitated the family's bon-adaptation in cancer caregivers. Positively redefining of the stressful situation was positively linked to family resilience (Greef *et al.*, 2014).

The results further show that families affected by HIV/AIDS are able to pull together and reframe the crisis situation, unlike in the cancer affected group where family members

seemed not to mobilise their internal strengths when faced with a challenge of caring for a member with a life threatening disease such as cancer. These results are in line with those of Setwaba (2015), who found that family hardiness escalated the level of stress in families caring for a member who is deteriorating due to HIV/AIDS.

6.9.3 F-COPES as moderating grief

F-COPES was also found in this study to be the moderator of grief. This implies that the families affected by HIV/AIDS have problem solving mechanisms within the nuclear family and those from outside the family that assist during times of stress. The outcomes of this research support those by Krikorian *et al.* (2013) who found that internal mechanisms like hope, dignity, and meaning in life protect one from suffering and foster well-being.

Members in the HIV/AIDS affected families seem to draw support from the external sources like the church and healthcare professionals. This is common in the HIV/AIDS affected as there are lay counsellors in the health facilities who are often the first support systems for the families. Spirituality can help the family members to acknowledge the importance of the loved ones and to heal the wounds (Pienaar *et al.*, 2011; Skovdal *et al.*, 2012).

F-COPES was found to escalate the level of grief in adolescents affected by cancer. F-COPES was found to escalate the level of grief in adolescents affected by cancer. This differs from findings by Greef *et al.* (2014), who found that connectedness within the family, the experience of control over life events, family routines, positive and supportive communication, redefinition of crisis situations, and a positive appraisal of the crisis situation were positively linked to family adaptation in families caring for a child diagnosed with cancer.

Figure 4 below is a diagrammatic representation of potential resilience factors as well as their moderating effect on grief experiences in each family type. It also represents that the paradigm shift of HIV/AIDS to chronic illness, moderated the experience of grief. The terminal nature of cancer however was found to increase the level of grief.

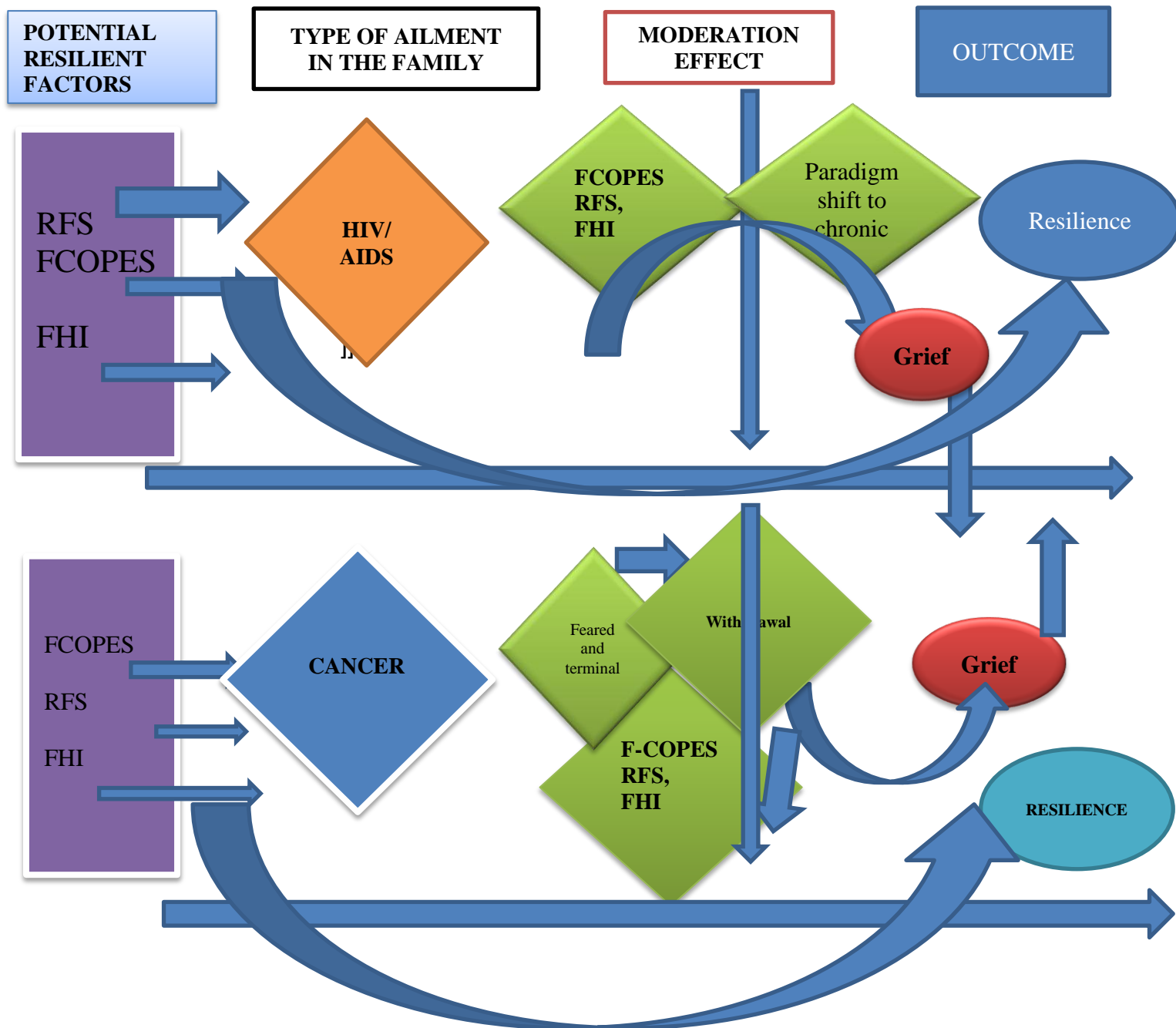


Figure 4: The resiliency model of stress, adjustment and adaptation: Summary of potential resilience factors and grief moderation in the study.

6.10 CONCLUSION

This chapter outlined the discussions on the results stipulated in chapter 5. The discussions were in relation to the experiences of ambiguous loss and grief reactions in families affected by HIV/AIDS and their control group of families affected by cancer. Family resilient factors that are unique to each family type were also discussed and their moderating effect on grief. The next chapter will discuss the conclusions, recommendations and limitations of this study.

CHAPTER 7

CONCLUSION, RECOMMENDATIONS, AND LIMITATIONS

7.1. INTRODUCTION

The previous two chapters gave an outline of the results and their contextualisation within the theoretical model for this study. Conclusions pertaining to the aim and objectives of this study will be discussed in this chapter. This research was aimed at identifying the ambiguous loss and grief reactions in adolescents affected by parental diagnoses of HIV/AIDS, and to further identify family resilience factors and their moderating effect on grief reactions.

The study was guided by the resilience model of family stress, adjustment and adaptation (ABCX) in finding the family resilient factors that moderate the grief symptoms.

This chapter will discuss the conclusion on the main aim and objectives of this research from the results. It will further indicate the limitations and recommendations for future research.

7.2. SUMMARY AND CONCLUSIONS ON THE EXPERIENCE OF AMBIGUOUS LOSS AND GRIEF REACTIONS IN ADOLESCENTS AFFECTED BY HIV/AIDS OR CANCER

The results of this study suggest that caring for an ailing parent is a great responsibility especially if it is done by adolescent children. The moment the parent begins to be sick, children experience varying feelings of loss and sadness. The inability of the parent to continue with his/her parental roles result in putting a burden on the children, leading to restructuring in the family. Adolescents find themselves assuming parental roles, a responsibility they are less prepared for; such break of boundaries constitutes what Boss referred to as 'ambiguous loss'. The experience of ambiguous loss was found to be the same in both the HIV/AIDS and the cancer affected groups in this study.

The experience of such ambiguous loss impacts on the children and leads to the experience of different forms of grief. They anticipate the death of their loved ones as soon as illness is announced leading to anticipatory grief. The forms of grief experienced by HIV/AIDS affected people are different from that experienced by cancer affected individuals. Adolescents from HIV/AIDS affected families tend to experience prolonged and delayed grief, whereas those from the cancer affected group experience prolonged and acute grief.

Demographics and disclosure of the disease status by the affected members do not have a significant impact on the experiences of grief. Family resilience factors among the HIV/AIDS affected group are similar to those present in the cancer affected group. They include F-COPES, FHI, and RFS. The resilience factors that have a moderating effect on grief are FACI, F-COPES, RFS, and FHI and were only significant for the HIV/AIDS affected group and the four indices did not have a moderating effect on grief in the cancer affected families. It can thus be concluded that the family qualities that moderate grief in HIV/AIDS affected adolescents have the opposite impact on the adolescent affected by cancer. The resilient qualities seemed to increase the level of grief for the cancer affected group.

Such a unique finding could be associated with the shift of HIV/AIDS to being chronic and manageable. The families affected draw strength from friends and family support and their level of hardiness, which is not the case for cancer which is still considered terminal and thus experienced as being deadly. On diagnosis, therefore, the family becomes acutely aggrieved and hold limited discussions that can draw some support to them from friends as it is the case with HIV/AIDS.

The introduction of the antiretroviral treatment and perception of HIV/AIDS being more like any other chronic illness has brought a paradigm shift to the families' perception of the illness. The uniqueness of this study is that moderation of grief has been demonstrated to be in line with perceived termination vs chronicity of the illness. The more chronicity is perceived, the more families become open for support and can bounce back within family support. This is in contrast to the feelings of termination, wherein support is not attracted by those affected and if it happens it fuels grief instead.

HIV/AIDS has moved from an illness that was stigmatised and did not attract support in recent years, but has now, with emergence of the antiretroviral treatment shown a huge paradigm shift. A unique finding for this study, which is in line with the argument made for the rise in life expectancy from 53 years in 2006 to 64 years in 2017 in South Africa, is due to the antiretroviral treatment, with a tremendous drop in reported deaths related to HIV/AIDS (STATSSA, 2017)

7.3. LIMITATIONS OF THE STUDY

The study had the following limitations:

- Most participants in the study were stable on treatment. Parents who did not receive treatment were not included in the study. One wonders how the results would have been affected if these had been included.
- The required number of participants was not reached for the cancer sample due to the fact that most patients in the oncology wards/ clinics were older and did not have adolescent children.
- Limited cultural groups were involved and the majority of the participants were Sepedi speaking.
- Due to the nature of the illness, some parents who did not disclose their status to their children were reluctant to have their children participate in the research.
- Most of the adolescents participating in this research were themselves HIV infected and on treatment; differing results could be found if most were not infected.
- The TRIG questionnaire was altered to meet the needs of the participants since their parents were still alive.
- The collection of data took long due to institutional challenges and access logistics, leading to a delay in the completion of this research. There have been changes regarding the rate of infection, treatment and life-span of HIV/AIDS infected individuals; probably differing results could have been found if this was not the case

7.4. RECOMMENDATIONS FOR FUTURE RESEARCH

The findings of this research indicate that adolescents from families with a parental HIV/AIDS and cancer diagnoses do experience forms of grief. The findings further indicate unique family resilience factors for each group and their moderating effect on grief. The forms of grief differed according to the nature of the parents' suffering. Such grief is experienced within the time when the families were going through extreme confusion associated with the ambivalence of having an ailing parent whom they experienced as being on the brink of death. The adolescents were forced into role reversal and intense experience of ambiguous loss as defined by Boss (2006).

Based on these results, the following recommendations are made:

- A longitudinal study that will assess the grief level with the progression of the illness and post death could be done in future to develop knowledge around grief manifestation in the context of both conditions and how best to assist families and especially the children cope with the immense emotional impact of parental incapacities during the period of their illness.
- Intervention for the HIV/AIDS and cancer patients should not to be restricted to the patient, but the children should be referred for psychological assessment and intervention to ease their experience of grief and emotional ambiguity around their role changes in the family and to give them strength to cope. Other measures that could be used include support groups for children affected by HIV/AIDS or cancer to strengthen the resilience.
- It is also noted that the pain that the cancer patients experience lead to caregivers not being able to access available resilience resources, thus escalating the amount of grief/ distress. More studies on the impact of cancer diagnoses in future should be done to inform such a process.
- Measures to strengthen families following the diagnosis of HIV/AIDS or cancer should be considered for implementation. This includes the giving of psychoeducation on the importance of disclosure and support to patients.

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2.2 Are you aware of what your diagnosis is? _____

2.3 When was the diagnosis made?

	Tick
0-1 year	
1-2years	
over 2 years	

a. Does anyone in the family have the same diagnosis?

YES		NO	

b. Does anyone in the family know about your diagnosis?

YES		NO	

c. If yes, who is the family member that you have disclosed the diagnosis to _____?

2.4 How many people stay with you at home? _____?

2.5 Ages of your children

Ages in years	Tick Relevant Box
0-5	
6-10	
11-18	
19-25	

2.6. Who of your family members assist during your period of ailment?

Caregiver	Tick Relevant Box	State age of caregiver
Partner		
Sibling		
Child		
Relative		

2.7 Which caregiver/s above know about your diagnosis

Caregiver	Tick Relevant Box	Knows about diagnosis
Partner		
Sibling		
Child		
Relative		

APPENDIX B: DEMOGRAPHIC INFORMATION AND GUIDING QUESTIONS FOR QUALITATIVE DATA

All information in this questionnaire is strictly confidential and your information will be anonymously processed. Please make a tick in the appropriate block.

1. Demographic information (for adolescent participants)

1.1 Gender

GENDER	Tick Relevant Box
Male	
Female	

1.2 Age

Age ranges	Tick Relevant Box
11-14	
15-17	
17-18	
18 and above	

1.3 Level of Education

Level of education	Tick Relevant Box	State the HLOE (highest level of education)
No education		
Primary school		
High school		
Tertiary		

1.4 Sibling Birth order

	Tick Relevant Box
First born	
Second born	
3 rd born	
Other (state)	

1.5 Home language

	Tick Relevant Box
N Sotho	
Tsonga	
Venda	
Other (specify)	

2 Please answer the following questions regarding your experience as a caregiver/child of a parent who is sick. If a question does not apply to you, please indicate by responding “Not Applicable (N/A).”

2.1 How did you feel when you first realised that your parent is not well?

2.2 How do you feel now about your parent(s)' ill health'?

2.3 What role are playing now that your parent(s) is ill

2.4 How do you feel about the role you are playing?

2.5 Have you experienced any feelings of loss since the time in which your parent(s) got ill? _____

2.6 Was any diagnosis made about your parent(s) illness? _____

2.7 Did your parent discuss the diagnosis with you? _____

2.8 How did the diagnosis make you feel?

2.9 What, if any, do you consider family qualities that usually play a role in dealing with challenges at home? And those that can assist currently wrt your parent(s)' illness?

APPENDIX C: GRIEF AND RESILIENCE QUESTIONNAIRES

SECTION A: BEREAVEMENT SCALE

THE TEXAS REVISED INVENTORY OF GRIEF (ADAPTED FROM THE TEXAS REVISED INTENTORY OF GRIEF-TRIG)

NAME: -----

AGE:----- GENDER:-----

RACE : white [] black [] other (Please list)-----

RELIGION : Protestant [] Catholic [] ZCC [] other (Please list)-----

How old was your parent when he/she got sick?-----

My parent got sick (tick only one box):

Within the past 3 months [] 3-6 months ago []

6-9 months ago [] 9-12 months ago []

My parent’s illness was: Expected [] Unexpected [] Slow [] Sudden []

PART 1: PAST BEHAVIOUR

Think back to the time when your parent got ill and answer all of these items about your feelings and actions at the time by indicating whether each item is completely True, Mostly True, Both True and False, Mostly False. Or Completely False as it applied to you after your parent got sick. Please check the best answer

Question	Compl etely True	Mostly True	True and false	Mostly False	Completely False
1. After my parent got sick, I found it hard to get along with certain people					
2. I found it hard to work well after my parent got sick					
3. After my parent got sick, I lost interest in my family, friends, and outside activities					
4. I felt a need to do things that my parent wanted to do					

5. I was unusually irritable after my parent got sick					
6. I couldn't keep up the normal activities for the first three months after my parent got sick					
7. I hide my tears when I think about my parent who is sick					
8. No one will ever take the place in my life of my parent who is sick					
9. I can't avoid thinking about my parent who is sick					
10. I feel it is unfair that my parent is sick I					
11. Things and people around me still remind me of my parent who is sick					
12. I am unable to the sickness of my parent					
13. At times I still feel the need to cry for my sick parent					

PART II: RELATED FACTS

Now please answer the following items by circling, either True or False.

Item	True	False
1. I was with my parent during consultation with the doctor		
2. I feel I have accepted that my parent is sick		
2. I feel I am functioning as well as I was before my parent got sick		
4 I seem to get upset each year at about the same time as when my mother fell sick		
5 Sometimes I feel I have the same illness as my parent who is sick		

SECTION C: RESILIENCE SCALES
FAMILY FUNCTIONING (FACI8)

Instructions

Decide how well each statement describes what is happening in your family. In the column headed Now, circle the number which best describes how often each thing is happening right now.

In my family...	Now				
	Never	Sometimes	Half the time	More than half	Always
1. In our family it is easy for everyone to express his/her opinion.	1	2	3	4	5
2. It is easier to discuss problems with people outside the family than with other family members.	1	2	3	4	5
3. Each family member has input in major family decisions.	1	2	3	4	5
4. Family members discuss problems and feel good about the solutions.	1	2	3	4	5
5. In our family everyone goes his/her own way.	1	2	3	4	5
6. Family members consult other family members on their decisions.	1	2	3	4	5
7. We have difficulty thinking of things to do as a family.	1	2	3	4	5
8. Discipline is fair in our family.	1	2	3	4	5
9. Family members feel closer to people outside the family than to other family members.	1	2	3	4	5
10. Our family tries new ways of dealing with problems.	1	2	3	4	5
11. In our family, everyone shares responsibilities.	1	2	3	4	5
12. It is difficult to get a rule changed in our family.	1	2	3	4	5

13. Family members avoid each other at home.	1	2	3	4	5
14. When problems arise, we compromise.	1	2	3	4	5
15. Family members are afraid to say what is on their minds.	1	2	3	4	5
16. Family members pair up rather than do things as a total family.	1	2	3	4	5

F-COPES

DIRECTIONS

First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then select the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then select the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3 or 4 to indicate how much you agree or disagree with the statement about your response.

1. Strongly disagree 2. Moderately disagree 3. neither agree nor disagree
 4 Moderately agree 5 strongly agree

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

	1	2	3	4	5
1. Sharing our difficulties with relatives					
2. Seeking encouragement and support from friends					
3. knowing we have the power to solve major problems					
4. Seeking information and advice from persons in other families who have faced the same or similar problems					
5. Seeking advice from relatives (grandparents, etc.)					
6. Seeking assistance from community agencies and programs designed to help families in our situation					
7. Knowing that we have the strength within our own family to solve our problems					
8. Receiving gifts and favors from neighbours (e.g. food, taking in mail, etc.)					
9. Seeking information and advice from the family doctor					
10. Asking neighbours for favors and assistance					
11. Facing the problems "head-on" and trying to get a solution right					

away					
12. Watching television					
13. Showing that we are strong					
14. Attending church services					
15. Accepting stressful events as a fact of life					
16. Sharing concerns with close friends					
17. Knowing luck plays a big part in how well we are able to solve family problems					
18. Exercising with friends to stay fit and reduce tension					
18. Exercising with friends to stay fit and reduce tension					
18. Exercising with friends to stay fit and reduce tension					
19. Accepting that difficulties occur unexpectedly					
20. Doing things with relatives (get-together, dinners, etc.)					
21. Seeking professional counseling and help for family difficulties					
22. Believing we can handle our own problems					
23. Participating in church activities					
24. Defining the family problem in a more positive way so that we do not become too discouraged					
25. Asking relatives how they feel about problems we face					
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems					
27. Seeking advice from a minister					
28. Believing if we wait long enough, the problem will go away					
29. Sharing problems with neighbors					
30. Having faith in God					

FHI

DIRECTIONS: Please read each statement below and decide to what degree each describes your family. Is the statement FALSE, MOSTLY FALSE, MOSTLY TRUE, TRUE, or NOT APPLICABLE about your family? Please indicate your choice in the appropriate space.

IN OUR FAMILY	Fals e	Mos tly Fals e	Mostl y True	Tr ue	Not Applic able	Offici al use
1. Trouble results from mistakes we make						
2. It is not wise to plan ahead and hope because things do not turn out anyway						
3. Our work and efforts are not appreciated no matter how hard we try and work						
4. In the long run, the bad things that happen to us are balanced by the good things that happen						
5. We have a sense of being strong even when we face big problems						
6. Many times I feel I can trust that even in difficult times that things will work out						
7. While we don't always agree, we can count on each other to stand by us in times of need						
8. We do not feel we can survive if another problem hits us						
9. We believe that things will work out for the better if we work together as a family						
10. Life seems dull and meaningless						
11. We strive together and help each other no matter what						
12. When our family plans activities we try new and						

exciting things						
13. We listen to each others' problems, hurts and fears						
14. We tend to do the same things over and over it's boring						
15. We seem to encourage each other to try new things and experiences						
17.It is better to stay at home than go out and do things with others						
17.Being active and learning new things are encouraged						
18. We work together to solve problems						
19. Most of the unhappy things that happen are due to bad luck						
20. We realise our lives are controlled by accidents and luck						

RFS

DIRECTIONS: Decide for your family whether you: **STRONGLY DISAGREE**; **DISAGREE**; are **NEUTRAL**; **AGREE**; or **STRONGLY AGREE** with the statements listed below. Indicate your choice in the appropriate *space*.

We cope with family problems by:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Official use
1. Sharing our difficulties with relatives						
2. Seeking advice from relatives						
3. Doing things with relatives (get together)						
4. Seeking encouragement and support from friends						
5. Seeking information and advice from people faced with the same or similar problems						
6. Sharing concerns with close friends						
7. Sharing problems with neighbours						
8. Asking relatives how they feel about the problems we face						