

**STRESS AND DYSFUNCTION IN FAMILIES CARING FOR MEMBERS  
PHYSICALLY DETERIORATING DUE TO HIV/AIDS IN LIMPOPO PROVINCE:  
RESILIENCE AS A MODERATING FACTOR**

**By**

**MOKGADI BEAUTY SETWABA**

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**SUPERVISOR: PROF. T- A. B. MASHEGO**

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## **DECLARATION**

I declare that the thesis hereby submitted to the University of Limpopo, for the degree of Doctor of Philosophy in Psychology has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

SIGNED:

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Initials and Surname:

Date

## **DEDICATION**

I dedicate this study to my dear husband, Mothiba, and our children Mahlatse, Neo, Refentse and Letago (Manefeta) who supported and encouraged me throughout this project.

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## **ABSTRACT**

The study aims at assessing the stress and dysfunction among families affected by the sudden reality of experiencing physically deteriorating family members due to HIV/AIDS progression, and to identify resilience factors that moderate the impact. Three-hundred and sixteen families were conveniently selected to participate in this study. The experimental group of the HIV/AIDS affected families ( $n=122$ ), with two control groups of families caring for family members ailing because of a non- HIV/AIDS physical ailment ( $n=132$ ) and the families not involved in the caring of any family member ( $n=62$ ). Family resilience and stress questionnaires were used to collect the data. Family resilience questionnaires included Family Hardiness Index (FHI), Social Support Index (SSI), Relative and Friend Support (RFS), F-COPES, Family Time and Routine Index (FTRI), Family Problem Solving Communication (FPSC) Family Attachment and Changeability Index 8 (FACI 8). The family caregiver stress was measured by the Relative Stress Scale. Univariate and multivariate regression analysis were used to determine the moderating effect of the family qualities on the stress levels, and specific qualities unique in the families that bounce back.

Stress was found to be high in the HIV/AIDS affected families when compared with the control families. Furthermore, the demographic information indicated that more stress was experienced in the HIV/AIDS affected families with a younger sick member and in poor economic conditions as well as when the sick person was a breadwinner. This indicated that stress elevation in the HIV/AIDS affected families was a function of economic conditions in the families and that caregivers may have experienced stress due to lack of proper resources and the stress of having sympathy for a young sick person who was expected to have a long life ahead of him or her. Social support (SSI), relative and friend support (RFS), and spending time together and engaging in similar routine collectively (FTRI) were found to moderate stress in HIV/AIDS affected families.

Further research is needed to highlight the dynamics and the relationship with stress elevation around the new trend of HIV/AIDS infection of the younger age group as well as the economic burden or the impact of lack of resources in caring for the infected. More in-depth research must also be done with an emphasis on the dynamics between stigmatisation, stress moderation and resilience of families using more diverse families engaging in various caregiving situations of sick family members within various ecological and socio economic conditions.

## TABLE OF CONTENTS

	<b>Page</b>
<b>1. ORIENTATION OF THE STUDY</b>	1
1.1 INTRODUCTION	1
1.2 STATEMENT OF THE PROBLEM	3
1.3 AIM OF THE STUDY	5
1.4 OBJECTIVES OF THE STUDY	6
1.5 RESEARCH QUESTIONS	6
1.6 HYPOTHESES	7
1.7 SIGNIFICANCE OF THE STUDY	7
1.8 CONCLUSION	8
<b>2. LITERATURE REVIEW</b>	9
2.1 INTRODUCTION	9
2.2 HIV/AIDS CRISIS IN SOUTHERN AFRICA	9
2.3 FAMILY STRESS	12
2.4 FAMILY CRISIS IN STRESSFUL SITUATIONS	12
2.5 THE TRAUMA OF CARING FOR HIV/AIDS INFECTED AND DETERIORATING FAMILY MEMBER	14
2.6. HIV/AIDS CAREGIVER STRESS SYNDROME	17
2.7 EMOTIONAL CONSEQUENCES OF HIV/AIDS ON THE FAMILY	20
2.8 THE STRESS OF CARING FOR A FAMILY MEMBER WITH A CHRONIC AILMENT	20
2.9 FAMILY RESILIENCE	22
2.9.1 Communication	24
2.9.2 Equality	24

2.9.3 Spirituality	25
2.9.4 Flexibility	25
2.9.5 Truthfulness	27
2.9.6 Hope	27
2.9.7 Family hardness	28
2.9.8 Family time and routines	28
2.9.9 Social support	29
2.9.10 Health	31
<b>2.10 CHARACTERISTICS OF RESILIENT FAMILIES</b>	<b>31</b>
<b>2.11 COPING AND FACTORS THAT INFLUENCE COPING IN STRESSFUL SITUATIONS</b>	<b>32</b>
<b>2.12 THE FUNCTIONS AND DIMENSIONS OF COPING</b>	<b>34</b>
<b>2.13 THE PSYCHOLOGICAL IMPACT OF HIV/AIDS IN THE FAMILY AND ITS IMPACT ON SOCIAL SUPPORT</b>	<b>36</b>
<b>2.14 EMOTIONAL REACTIONS OF FAMILY MEMBERS TO THE DISCLOSURE OF HIV STATUS OF THE FAMILY MEMBER</b>	<b>38</b>
<b>2.15 STAGES OF HIV PROGRESSION</b>	<b>39</b>
2.15.1 Acute HIV infection (the window period)	39
2.15.2 Seroconversion	39
2.15.3 HIV infection before the onset of symptoms	39
2.15.4 Progression from HIV infection to HIV-related disease and AIDS	40
<b>2.16 CONCLUSION</b>	<b>40</b>
<b>3. THEORETICAL FORMULATION</b>	<b>41</b>
<b>3.1 INTRODUCTION</b>	<b>41</b>
<b>3.2 OPERATIONAL DEFINITIONS</b>	<b>41</b>
<b>3.3 THEORETICAL FRAMEWORK</b>	<b>42</b>
3.3.1 The resiliency model of family stress, adjustment	

and adaptation	42
3.3.1.1 The adjustment phase	44
3.3.1.2 The adaptation phase	45
3.3.2 Family stress theory	46
3.4 CONCLUSION	47
<b>4. CULTURAL CONTEXTUALIZATION OF FAMILY LIFE AND HIV/AIDS</b>	<b>49</b>
4.1 INTRODUCTION	49
4.2 THE BOND WITHIN THE EXTENDED FAMILY STRUCTURE	50
4.3 THE IMPACT OF HIV/AIDS ON FAMILIES, COMMUNITIES AND THE SOCIETY	51
4.4 CULTURAL CONTEXTUALIZATION OF AFRICAN FAMILY LIFE	52
4.5 CHANGING STRUCTURES AND FUNCTIONS OF FAMILIES AFFECTED BY HIV/AIDS	53
4.6 CULTURAL PERCEPTION OF HIV/AIDS	54
4.7 FAMILY AND HOUSEHOLD RESPONSES TO HIV/AIDS	55
4.8 CONCLUSION	56
<b>5. RESEARCH METHODOLOGY</b>	<b>57</b>
5.1 INTRODUCTION	57
5.2 RESEARCH DESIGN	57
5.3 SAMPLING	57
5.4 INSTRUMENTS	58
5.5 PROCEDURE	62
5.6 DATA ANALYSIS	63
5.7 ETHICAL CONSIDERATIONS	64

5.7.1	Permission	64
5.7.2	Confidentiality	64
5.7.3	Anonymity	64
5.7.4	Participants' after care	65
5.8	CONCLUSION	65
<b>6. FINDINGS</b>		66
6.1	INTRODUCTION	66
6.2	DEMOGRAPHIC CHARACTERISTICS OF THE STUDY PARTICIPANTS AND THE POSITION OF SICK FAMILY MEMBERS	66
6.3	STRESS AND RESILIENCE OUTCOMES	69
6.3.1	Experience of stress by families	69
6.3.2	Experience of stress by demographics	71
6.3.2.1	Age status	72
6.3.2.2	Experience of stress by language groups	72
6.3.2.3	Experience of stress by income	72
6.3.2.4	Gender status	73
6.3.2.5	Demographic information of the sick person within the family	73
6.3.2.6	Level of stress and the gender of a sick member in the family	74
6.3.2.7	Level of stress and the age of a sick member in family	74
6.3.2.8	Position of a sick member in the family	74
6.4	POTENTIAL RESILIENCE FACTORS BY FAMILY TYPE	75
6.4.1	Potential resilience factors among families caring for family members physically deteriorating due to HIV/AIDS	75
6.4.1.1	Family time and routine index (FTRI) factor	75

6.4.2 Potential Resilient factors among families caring for family members physically deteriorating due to any other chronic illness	76
6.4.2.1 Social Support index (SSI) factor	77
6.4.2.2 Family Hardiness index (FHI) factor	79
6.4.2.3 Family time and routine index (FTRI) factor	80
6.4.3 Potential Resilient factors among families not involved in caring for an ailing family members	81
<b>6.5 FINDINGS ON THE MODERATION EFFECT OF FAMILY RESILIENCE FACTORS ON STRESS</b>	<b>81</b>
6.5.1 Stress Moderation effects highlighted for families caring for members physical deteriorating due to HIV/AIDS	82
6.5.1.1 Univariate regression analysis	82
6.5.1.1.1 Moderating factors for stress as highlighted by the univariate regression analysis	83
6.5.1.2 Multivariate regression analysis	84
6.5.1.2.1 Emerging moderating factors by multiple effect	85
6.5.2 Stress moderating effects highlighted for families caring for Members ailing due to any other chronic condition	86
<b>6.6 THE CONCLUSION OF THE UNIQUE FINDINGS OF THE RESILIENCE AND STRESS MODERATION FACTORS</b>	<b>87</b>
<b>7. DISCUSSION</b>	<b>88</b>
<b>7.1 INTRODUCTION</b>	<b>88</b>
<b>7.2 THE DEMOGRAPHIC FACTORS OF THE CAREGIVERS AND THE SICK PERSON WITHIN FAMILIES IN THE STUDY</b>	<b>89</b>
7..2.1 Age of caregivers	89

7.2.2 Gender differences in caregiving	90
7.2.3 Sick member position in the family	90
7.2.4 Gender of the sick family member	90
7.2.5 Age of the sick family member	91
7.3 EXPERIENCE OF STRESS BY DIFFERENT FAMILIES	91
7.4 POTENTIAL RESILIENT FACTORS AMONG HIV/AIDS AFFECTED BY ANY FAMILIES	93
7.5 POTENTIAL RESILIENT FACTORS FOR FAMILIES AFFECTED CHRONIC CONDITION BESIDES HIV/AIDS	96
7.6 THE MODERATION EFFECT OF RESILIENCE FACTORS ON STRESS ACCORDING TO FAMILY TYPOLOGY	98
7.6.1 Moderation of stress by family togetherness and connectedness	100
7.6.2 Social Support as a moderator of stress	101
7.6.3 Communication as a stress moderator	102
7.6.4 Family Hardiness as a moderating factor	103
7.7 CONCLUSION	103
<b>8. CONCLUSION, RECOMMENDATIONS AND LIMITATIONS</b>	105
8.1 INTRODUCTION	105
8.2 SUMMARY AND CONCLUSION OF THE FAMILY GROUPS WITH REGARDS TO RESILIENCE FACTORS USED AND STRESS MODERATION	105
8.3 LIMITATIONS OF THE STUDY	108
8.4 RECOMMENDATIONS FOR THE FURTHER RESEARCH	108
<b>9. REFERENCES</b>	111
<b>10 APPENDICES</b>	123

## **LIST OF TABLES**

Table 1: Demographic results of the research groups	67
Table 2: Mean experience of stress by family type	70
Table 3: ANOVA between family typology and stress	71
Table 4: Demographic characteristics of the study participants	71
Table 5: Comparison of the frequency of experience of stress levels by demographics between families caring for chronically ill and HIV/AIDS sufferers	73
Table 6: Pearson's correlation between FACI and FTRI	76
Table 7: Pearson's correlations for FACI and other resilient factors in families caring for members suffering from any other chronic illness	77
Table 8: Pearson's correlations for FACI and SSI in families caring for members suffering due to any chronically ill family members	78
Table 9: Pearson's correlations for FACI and FHI in families caring for members suffering due to any chronically ill family members	80
Table 10: Pearson's correlations for FACI and FTRI in families caring for members suffering due to any chronically ill family members	81
Table11: The results of the univariate regression analyses (Outcome=stress)	82
Table 12: The results of the multivariate regression analyses (Outcome=stress)	85
Table 13: Multivariate Regression Analyses Summary	86

## **LIST OF FIGURES**

Figure 1: The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, Thompson & McCubbin (1996); McCubbin & Thompson, 1991)	44
Figure 2: McCubbin Resiliency model of stress, adjustment and adaptation. Families caring for member physically deteriorating due to HIV/AIDS.	95
Figure 3: McCubbin Resiliency model of stress, adjustment and adaptation. Families caring for member physically ailing due to any chronic condition.	97
Figure 4: The resiliency model of stress, adjustment and adaptation: Summary of stress moderation and resilience factors in the study.	99

## **CHAPTER 1**

### **ORIENTATION OF THE STUDY**

#### **1.1 INTRODUCTION**

HIV/AIDS is a condition that affects families in a profound and tragic way, leaving the family stressed and dysfunctional. According to Collins and Leibbrandt (2007), HIV/AIDS touches at the central part of families, either drawing them closer together or driving them further apart. When a family member is diagnosed with HIV, the impact goes beyond the individual themselves, affecting other family members (DeGennaro & Zeitz, 2009). Furthermore, when a family member, particularly a parent, becomes sick, is weakened or dies, everyone in the family is collectively affected. Knowing that a family member is diagnosed HIV positive is often experienced as stressful (Bor, du Plessis & Russell, 2004). Families with members physically deteriorating due to HIV/AIDS progression take an enormous stress and burden in terms of caregiving (Makoae, 2009). The eventual process of physical deterioration of a family member is often perceived as devastating since it affects various family structures and functions and disproportionately increases the vulnerability of families living in poverty (UNAIDS, 2004).

HIV/AIDS hinders development in the hardest hit countries, exacting a disastrous toll on the families affected and erasing decades of health, economic and social progress, reducing life expectancy by years, deepening poverty, and contributing to and exacerbating resource shortages (UNAIDS, 2004). The cost of treatment, travelling to medical appointments and the loss of income when they are unable to work due to ill health is enormous.

In many parts of the world, single-parent and step-families are created by parental death and orphanhood due to the HIV/AIDS pandemic, which leads to the emergence of new family forms where the middle generations are skipped within families. There are various factors around the globe which lead to a growing number of older adults being pressed into caregiving service

(Miller, 2006; Zimmer & Dayton, 2003). The parent generation has succumbed to AIDS and AIDS related illnesses such that families are made up of grandparents and orphaned grandchildren. In other cases where grandparents are not available to care for orphaned grandchildren, families are headed by the very orphaned children (Babour, 1994; UNAIDS, 2007).

Changes in the family structure affect the general functioning and family resilience as the burden of caring is often seen from the systemic point of view. Although care giving is often perceived as the responsibility of primary caregivers, in families, the task is often a collective joint effort. A crisis that befalls families usually impacts on the family members as a whole (Ice, Sadruddina, Vagedesa, Yogo, & Juma, 2012). This implies that the experiences of caregivers and responses in this research will be viewed as representing the experiences and feelings of the rest of the family members. Ice et al., (2012) state that globally, a growing number of grandparents are caring for their grandchildren. The impact and burden associated with HIV/AIDS increases in custodial grandparenting; however, this may differ by culture. In other cultures, the caregiving role has been shown to be a significant source of stress for older adults. In cultures in which grandparents are more commonly involved in the care of young children, increasing caregiving roles may not be viewed as stressful.

Although research has previously focused on the pathogenesis of HIV/AIDS on individuals, a number of studies have highlighted the importance of resilience as a systematic quality within the family, focusing on the salutogenetic approach (Hawley & De Haan, 1996; Walsh, 1996; Pule, 2010). Family resilience emphasises that the potential family has to emerge stronger over time after facing a stressful and challenging situation such as physical deterioration of a family member infected with HIV/AIDS. This, according to Hawley and De Haan (1996), is the path that the family follows as it prospers over adversity. It seems like there has been neglect of how families actually bounce back irrespective of the impact of the trauma and the stress exerted on them by HIV/AIDS.

Despite the high prevalence rates of HIV/AIDS infections and deaths in sub-Saharan African families, somehow, there appears to be undocumented unique ways in which African families specifically, adjust to stressful traumatic situations (UNAIDS, 2004). This includes sparse research around the issues of coping with HIV/AIDS physical deterioration and the eventual slow progressive death and how that impacts on families' wellbeing and functioning. The increased number of illnesses and diseases as well as high mortality rate in the African communities and families impact negatively on families to a point of sometimes rendering them completely stressed and dysfunctional. There is, however, still an element of sustenance of quality of life, which could be explained by resilience that is in most cases unrecognised and underestimated. The study aims to identify and explore those specific resilience factors used by families, especially African families, which could moderate the impact of stress in the affected families resulting in stability.

## **1.2 STATEMENT OF THE PROBLEM**

The number of people living with HIV/AIDS worldwide has continued to grow reaching an estimated 33.4 million by 2008. In 2012 the numbers escalated to 35.3 million (UNAIDS, WHO & UNODC, 2013). Globally the spread of HIV infections appeared to have peaked in 1996 when 3.5 million new infections were recorded. In 2008 new infections were estimated at around 2.7 million. Sub-Saharan Africa remains the most heavily affected region, accounting for 71% of all new HIV infections in 2008. Moreover, sub-Saharan Africa is reported to have 22.4 million people living with HIV and there are 15 million AIDS orphans (children less than 18 years) who have lost one or both parents to AIDS. AIDS related deaths appeared to have peaked in 2004. In 2008 there were 2 million HIV/AIDS related deaths reported globally, and of this number 1,4 million occurred in sub-Saharan Africa, making Africa the continent most seriously affected by the epidemic. For 2011 the prevalence rate differs substantially with low prevalence figures in North African countries and the highest prevalence rates reported in Southern Africa (UNAIDS et al., 2013).

According to UNAIDS et al., (2013), 5.7 million South Africans were living with HIV/AIDS in 2007, which was more than in any other country in the world at that time. Just fewer than 12% of South Africans, from a total of 48 million, had HIV/AIDS. Statistics indicate that South Africa had the highest number of people living with HIV/AIDS in Africa (UNAIDS et al., 2013). It is believed that in 2008 alone, over 250 000 South Africans died of AIDS, and by 2010, 280 000 South Africans had already died of HIV/AIDS (UNAIDS, 2010). Globally over 20 million have died since the first cases of AIDS were identified in 1981, and the impact on families has been devastating (UNAIDS, 2010; Ala, 2001). Specifically 17.8 million children have lost one or both parents to AIDS (UNAIDS et al., 2013). The generation of orphans and the new family forms that accompany it are a formidable challenge to policy-making on child and family issues at the national level and in international development cooperation (Barbour, 1994; UNAIDS, 2004). While some family members seem to be experiencing stress due to the overwhelming impact of sudden realization of status and caring for their HIV/AIDS infected members, some families are somehow resilient and able to revert back to their usual functioning, sometimes even to higher levels of functioning than before.

Research has recognized the burden faced by families living with a chronically ill relative (Roychaudhuri, Mondal, Boral & Bhattacharya, 1995; Boye, Bentsen, Ulstein, et al., 2001). This therefore leads to the development of health services that not only focus on the treatment of patients, but also meet the needs of the family (Hughes, Abbati-Yeoman & Budd, 1996; Solomon, 1996). The chronic illness of the family member is viewed as an ongoing stress, and families engage in a variety of coping strategies to deal with the demands of the current situation (Scozufca & Knipers, 1999; Birchwood & Cochrane, 1990; Solomon & Draine, 1995).

In the South African context, investigating stress and resilience from a family perspective is relatively recent. Literature shows that there is a conspicuous lack of empirical data focusing specifically on the stress and resilience of families caring for members infected and physically deteriorating due to the progression of HIV/AIDS. Much of the literature is focused on the stress of

individuals and how the disease affects their quality of life (Kachik, 1999; Darling, Olmstead & Tiggleman, 2010; Niven & Khussen, 1999). However, very little is known about the levels of stress, dysfunction and resilience within families affected by a family member's deterioration.

The impact of the epidemic is particularly hard on women in families, i.e. wives, mothers, daughters and grandmothers, as the burden of care usually falls on them (Kipp, Yebwa, Rubaale & Bajena, 2007). Girls frequently drop out of school to care for sick parents or for younger siblings and this occurs most frequently among the girls than it does for boys.

Older women often take on the burden of caring for ailing adult children with subsequent adoption of their orphaned children when the sick die with responsibilities to cater for the children's living expenses and food. These older women are often socially isolated because of AIDS-related stigma and discrimination with subsequent lessening of family support and heightened rejection even by other family members (Sikkema, Kalichman, Hoffmann, Koob, Kelly & Heckman, 2000; UNICEF, 2004). Despite the above circumstances families find themselves, some families remain remarkably resilient and functional. Numerous literatures hold that the strength of families and family networks is instrumental in determining how well families and communities cope with the disease and its consequences (Sikkema, Kalichman, Hoffmann, Koob, Kelly & Heckman, 2000; UNICEF, 2004).

### **1.3 AIM OF THE STUDY**

The aim of the study was to assess the stress levels and dysfunction among families affected by the sudden reality of experiencing physically deteriorating family members due to HIV/AIDS progression, and to identify resilience factors that moderate the impact.

## **1.4 OBJECTIVES OF THE STUDY**

The objectives of the present study were:

- To explore the extent to which families experiencing sudden realities of physically deteriorating member due to HIV/AIDS progression, experience stress and dysfunction.
- To assess how stress levels in such families respond to available resilience factors.
- To determine if there is uniqueness in resilience factors that operate among families affected by HIV/AIDS compared to those that are not affected (or not affected by HIV/AIDS).
- To determine if there is any relationship between resilience strategies families use and the demographic background of family caregivers, viz. gender, age and role or position held in the family by the ailing family member.

## **1.5 RESEARCH QUESTIONS**

- To what extent do families that experience sudden realities of physically deteriorating member due to HIV/AIDS progression, experience stress and dysfunction?
- How do stress levels in such families respond to available resilience factors?
- Which resilience factors operate among families affected by HIV/AIDS and how do they compare resilience factors among families not affected (or not affected by HIV/AIDS).
- Is there any relationship between resilience strategies families use and the demographic background of family caregivers, viz. gender, age and role or position held in the family by the ailing family member?

## **1.6 HYPOTHESES**

- Families experiencing sudden reality of physically deteriorating members due to HIV/AIDS are likely to report stress symptoms and dysfunction, and this differs according to the demographic background.
- Resilience will be more predominant among families with lower levels of stress than among those with higher stress levels.
- Stress levels in families caring for a sick member will be moderated by unique resilience factors within families and will differ according to the nature of the condition suffered by the sick member.
- Resilience factors in families experiencing sudden reality of physically deteriorating members due to HIV/AIDS will differ in uniqueness from those of families that are not affected (or not affected by HIV/AIDS).

## **1.7 SIGNIFICANCE OF THE STUDY**

The impact of physical deterioration due to HIV/AIDS on family members can push the family into complete dysfunction as the member requires specialized care. This situation may demand extreme family role changes for which the family may not be prepared, consequently making the transition come as a shock to family members who may not have the necessary skills to deal with the demands (Boss, 2002).

The present study aims at highlighting the role of resilience in moderating stress associated with trauma around role-change transition. By highlighting resilience, the study will also demonstrate the significance of health promotion, a salutogenetic paradigm which, unlike the pathogenetic approach promotes the notion of sustainable development and characteristics that contribute to growth and development of the family system.

Policy makers, family workers and supportive community organizations need to understand the dynamics of the impact of HIV/AIDS on family structures and caregivers. It is therefore, of crucial importance that studies such as the present one are conducted in order to explore the challenges that affected families are faced with. This will lead to finding a solution to the problem, leading to the development of relevant family qualities and the implementation of resilience factors that reduce stress and dysfunction, especially within the caring families. Equally, this will lead to the strengthening of family and community values eroded by the HIV/AIDS pandemic.

## **1.8 CONCLUSION**

This chapter aimed at introducing the background of the study regarding stress and dysfunction experienced by families caring for members physically deteriorating due to HIV/AIDS. The statement of the problem, aims and objectives, research questions and hypotheses as well as the significance of the study were also outlined. The next chapter will focus on the literature relevant to the study.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This section deals with the review of literature relevant to this study. The issues and concepts of family stress and dysfunction will be explored. Arguments and conclusions of the previous researchers as compared to the aims and objectives of the study will be reviewed. The crisis of HIV/AIDS in Southern Africa, how families react to crisis in stressful situations, the trauma of caring for HIV/AIDS infected and physically deteriorating family member, HIV/AIDS caregiver syndrome as well as the emotional consequences of HIV/AIDS on families will be explored. These will be followed by how the family copes with the demands of resilience factors, characteristics of resilient families, factors influencing coping and issues related disclosure. Furthermore, family cultural issues including cultural contextualization of the family, changing functions and structures of family due to HIV/AIDS, cultural perception of HIV/AIDS as well as family and household responses to HIV/AIDS are also highlighted.

#### **2.2 HIV/AIDS CRISIS IN SOUTHERN AFRICA**

Considering the endemic poverty, scarcity and multiple social ills in Africa, the HIV/AIDS epidemic may be the “last straw” for the people of Southern African countries. As elsewhere in Africa, the sub-Saharan countries are beset by a wide range of economic, social and political problems besides the epidemics. This includes extreme disempowering and debilitating chronic poverty; economic recessions, foreign debt, the effects of economic structural adjustment programmes and massive unemployment. The HIV/AIDS epidemic constitutes not only the worst scourge and onslaught with which people of Africa must contend, they also occur in a context in which the effects of the epidemics and key issues which they engender are juxtaposed with the multiplicity of a range of societal problems (UNAIDS, 2004).

Historically, Southern African countries were the last in the region to experience the pandemic, as it spread down the continent from East Africa. Uganda is the only African country to have succeeded in overcoming the epidemic, through early concerted awareness and prevention strategies. Botswana, Zimbabwe and South Africa have become the hardest hit by the disease among all African countries. The demographic consequences of the HIV/AIDS epidemics are described in numerous global agency sources and in the research and policy literature, and may be consulted independently. (UNAIDS, 2004).

Southern Africa is the sub region worst affected by the pandemic globally. Indicators of how the epidemics and their consequences have ravaged the countries include mortality rates for worst affected age groups. In 1999, infant mortality rates for the sub region were nearly 70 percent higher than they might have been without AIDS; in Zimbabwe, 72 percent higher. Child mortality rates have proved to be even greater: by 2010 the child mortality rate in South Africa is projected to be more than twice as high as it would be without AIDS, and in Zimbabwe, three and a half times as high (United States Census Bureau, 1999).

Although earlier discussions on HIV/AIDS focused on prevention and persons infected with HIV, attention is more recently being directed to the impact of the epidemics on non-infected family members, or those affected emotionally, economically, socially and physically by the illness and the death/s of a person/s with AIDS. Most attention though has probably been given to the children of persons with AIDS – as these children and the so-called AIDS orphans have been the focus of the mass media and international agencies such as UNAIDS and UNICEF. However, many HIV infected adults not only have children but also parents – who are likewise affected by their adult children's illness. The consequences of the epidemic for older persons and parents of adults with AIDS have been comparatively overlooked. Greater attention has been given to their role as grandparents caring for AIDS orphans, than to their interrelationship with AIDS sick adult children. Before they assumed the role of caring for AIDS orphans, however, older persons

were burdened with financial demands relating to the health care costs and the provision of material support to both their AIDS sick adult children and the children's dependents.

In South Africa women who are 60 years and over and who receive the social old age pension expend the greater part of their grant income on meeting the needs of their AIDS sick adult children and affected grandchildren and some of the children whom themselves may be infected with the virus or have AIDS (Ferreira, Keikelame & Mosaval, 2001). There are caregiving issues that have an enormous impact on older persons, and women in particular. These include the physical and health effects of the strain of caregiving, additional domestic responsibilities, insufficient income and food deprivation, community stigmatization, and the emotional effects of caring for a terminally ill person and coping with the loss of a child or children to AIDS. The impact of AIDS on older parents can moreover be particularly harsh, given the often lengthy periods of illness and disability, and their fears for the future.

In African countries, very little if any public assistance is available to persons with AIDS, but even less or nothing is available to caregivers. Persons with AIDS therefore rely on intergenerational support arrangements, which mean that sick adult children and their dependent children often reside with elderly parents. If adult children live elsewhere, for migrant labour or other reasons, and if they develop AIDS, most will return to their parental home to be cared for by a parent until they die (Ntozi & Nakaijwa, 1999).

HIV/AIDS has been described as one of the worst assaults on human dignity in Southern Africa today (cf. Secure the Future, 2001). The Secure the Future (TSF) Programme, being conducted in Botswana, Lesotho, Namibia, South Africa and Swaziland (and recently in several West African countries) is one of several multinational and bilateral programmes carried out in the subregion to address the social and economic effects of the epidemics. The TSF programme aims specifically to improve the situation of women and children affected by AIDS, whom it claims are hardest hit in terms of caregiving demands and situations of deprivation. The programme maintains that

challenges of the epidemics call for a multisectoral response from governments, the business community, civil society, community based organizations and non-governmental bodies.

It points out that historically, most efforts, guided by government strategies, have focused on prevention (awareness, information and education); only later was there a focus on care for persons already infected with or affected by HIV/AIDS. The programme co-ordinators contend that the burden of caring for the terminally ill has been overwhelming and that most health institutions have been unable to cope. As a result, this responsibility has devolved to family members (mainly women and girl children) and community organizations, all of whom and which need to be supported.

### **2.3 FAMILY STRESS**

Family stress is defined by Boss and Mulligan (2003) as pressure tension in the family which has the ability to disturb the equilibrium of the family. This indicates that the family goes through a process of change in routines, patterns of interaction, and is also affected by various types of movements and occurrences in the family. Family stress therefore, could result from events and situations that have the potential to cause negative change for the collection of members in the family to the extent that this causes tensions and strain, leading to disequilibrium and symptoms of disturbance (Boss, 2002). The impact of stress depends on how the family interprets or perceives it and the meaning they attach to the event. The intensity of stress is determined by the family vulnerability and the resources available for the family to deal with the stressor (McCubbin & McCubbin, 2001).

### **2.4 FAMILY CRISIS IN STRESSFUL SITUATIONS**

McCubbin and McCubbin (2001) define a crisis as “a state of imbalance, disharmony and disorganization in the family system” (p. 22). However, although the crisis situation marks family vulnerability, the family is still faced with an opportunity for constructive changes in its patterns of functioning.

Although this opportunity is available, these vulnerable families are partially characterized by imbalance and disharmony, a situation which is unfortunately only exacerbated by the following cyclical interaction (McCubbin & McCubbin, 1996; 2001).

The crisis experienced by families is exacerbated by a pile-up of demands (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996). There are nine categories of stressors that contribute to a pile-up of demands and in turn, create a crisis situation. These include the initial stressor and its related hardships, normative changes in the family; prior family stressors that have accumulated over time; situational demands that arrive unexpectedly; efforts that the family have made to cope; ambiguity between the larger social system and the family about how families should cope during times of crisis; new patterns of functioning which the family has adopted to cope which exert more demands; new patterns of functioning which may be incongruent with the schema and paradigms of the family; and finally, old patterns of functioning which established within the family but which may be incongruent with new patterns (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996).

The second factor that exacerbates the crisis is the inadequacy of the family or deteriorating established patterns of functioning (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996). Established patterns of functioning were explained in the adjustment phase and carry over into the adaptation phase. Some of these patterns provide stability and harmony and are preserved as the restrained and restored patterns of functioning of the family. In addition, new patterns of functioning must be implemented (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996). The nature of these patterns depends on what is needed to facilitate adaptation considering the nature of the crisis.

New patterns of functioning focus on five areas. These include different patterns that impact and change the rules and boundaries within the family; routines, relationships and roles; coalitions within the family system;

communication patterns, transactions and interactions with the community. The purpose of new patterns of functioning is to initiate disruption within the family dynamics which helps them cope, restore balance and achieve adaptation (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996). The retained and restored patterns of the family functioning, as well as new patterns of functioning interact with the situational appraisal of the crisis, problem solving and coping strategies, and resources of the family. This interaction ultimately leads to family adaptation (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996).

## **2.5 THE TRAUMA OF CARING FOR HIV/AIDS INFECTED AND DETERIORATING FAMILY MEMBER**

Considering the stage to stage progression of HIV/AIDS and deterioration of the ailing family member, intense care will always be a challenge for family caregivers. Studies in sub-Saharan Africa indicate that family members experience stress and financial burden as a result of caring for relatives with HIV-related illnesses (Ankrah, 1993; Bindura-Mutangadura, 2000; Baylies, 2002). Seeley, Kajura, Bachengana, Okongo, Wagner and Mulder (1993) argued that as a result of protracted AIDS illness, household resources are eroded and families are burdened as their capacity to provide care is gradually diminished. In most instances family caregivers lack the essential skills, knowledge and emotional support, thus rendering care giving extremely stressful and traumatic. Because of the physical demands and psychological stressors associated with care giving, family caregivers are the hidden victims of the epidemic. Tolliver (2001) and most of them according to Kipp and Nkosi, (2008) display symptoms that suggest high levels of stress and low self-reported quality of health.

Most studies have stressed the negative impact on caregivers when illness has progressed. For instance, care giving for the patients with chronic diseases has been associated with difficulties in such areas as finances, social wellbeing, and psychological problems such as depression, guilt, shame, frustration and stress (Bond, Clark & Davies, 2003). Young caregivers

would be more at a loss because they do not have the capacity to provide the caregiver services due to maturity which will be natural if the caregiver is older. In the African culture parental responsibility is to care for the young and once the child grows it is expected of them to take over the caregiving responsibility. Death of a child is the least expected in line with the 'value for children' concept for the Africans in the trend within the HIVAIDS pandemic where children die before their parents.

According to Hurwitz and Reinhardt (1995), there are two aspects of care giving which involve caregiver duties, meaning the activities and responsibilities of the caregiver and caregiver burden which refers to the negative outcomes of providing care for chronically ill family members, part of which is stress.

Care giving-burden is viewed as a major traumatic experience of caregivers. The caregivers may feel overloaded if they encounter hardships in their role, and the chronic and progressive nature of AIDS is often perceived as a prime mechanism behind the expansion of stressors among AIDS caregivers (Pearlin, Aneshensel & LeBlanc, 1997). In AIDS care corporeality of the patients is central to the caregivers' consciousness, however, it seems like there has not been much attention paid to how this phenomenon influences care giving experiences, especially in relation to stress. Chronic illness may introduce a high degree of vulnerability, and family caregivers play a crucial role in counteracting chronic illnesses.

The body of HIV/AIDS sufferer often undergoes radical changes which is disturbing for both the sufferer and his family (Lawler, 1998). Hence, caring for a chronically ill individual is primarily about caring for a body whose level of independence may be intermittently or permanently limited. It has also been observed that family members encounter difficulties with various aspects of the sufferer's bodily functioning, which they need help to cope with. The body is multidimensional, and although its physical and biological aspects tend to be emphasized in the medical discourse, in care giving activities, where both actions and emotions are oriented towards the body that is cared for; bodies

are also experienced from the way a person experiences herself or himself (phenomenological) and the way a person is experienced in the social context by the society (Kelly & Field, 1996).

Severe illness and deterioration necessitate the need to accept help for activities that are essentially private, thus leading to awkward situations whereby the social rules of touching and showing the body parts are contravened (Lupton, 2003). This is often perpetuated by gender mismatch, secrecy and resistance to care giving and care receiving on the part of the sufferer. The caregivers who encountered resistance from the care-recipients, or who felt restrained when they needed to access the body of the patient for purposes of care, experienced anger and frustration. Generally, formal and informal care suggests that taking care of the bodies of other people may not be experienced with detachment (Lawler, 1998; Lawton, 1998; Twigg, 1998; Lupton, 2003). Two factors at play around touching another person's body in the case of older sick person create boundary problems for a younger caregiver, and this will be in line with social values regarding respect for adults and issues of privacy. This is often an issue when the sick member is of the opposite sex and the caregiver's parent (Lupton, 2003).

As HIV/AIDS sufferers progress through different stages of the disease, changes to physical appearance due to HIV-related opportunistic illnesses are often observed. This happens especially at the last two stages of AIDS. The diseases often include Pneumocystic Carini Pneumonia (PCP), chronic diarrhea, extreme weight loss, AIDS dementia among others (Persson, 2004). It further suggests that HIV-related illnesses typically alter or disfigure the body conspicuously, especially HIV-related wasting which occurs as a result of noncompliance to antiretroviral treatment. The symptoms are often stressful and traumatic for caregivers to deal with on a daily basis.

Other aspects of physical care giving could be complicated by the social relationship between the caregiver and care-recipient, the sufferer's behaviour, health concerns (such as the risk of infection), and other subjective tendencies, especially feelings of fear and disgust. Another stressful issue

could be the fear of contact with a patient's bodily fluids such as blood and excreta. Such fear breeds anxiety irrespective of whether the HIV status of the patient was known or not. The fear is that most of them are ignorant of the precautionary measures, for example using gloves and detergent and are thus at risk. Such vulnerability is brought by fear of hurting the care-recipient and protecting the person from feeling stigmatized (Makoae, 2009).

Examination of bodies of care-recipients by the caregivers is common practice and this comes with the discovery of some bodily changes that alert caregivers of the reality of the status of health for their care-recipients. Caregivers often monitor and compare the health condition of the relative across time as they deteriorate in front of them with subsequent experience of trauma.

Care giving could often be complicated by the emotions of the caregivers, which usually emerge from noticing the changes of the patient's bodily systems, especially when the patient deteriorates. Seeing a chronically ill family member often make caregivers compare the premorbid physical appearance of the care-recipients with the current situation, and they are often perplexed by the extreme changes observed. Such changes include progressive weight loss or transformed features, as well as physical changes to the skin, eyes and other facial features among HIV/AIDS patients. Such experiences are bound to contribute to experience of sympathy, pain, as well as continuous psychological trauma (Makoae, 2009).

## **2.6 HIV/AIDS CAREGIVER STRESS SYNDROME**

The trauma of working with individuals diagnosed with AIDS is the serious reality that the appearance and health of the person with AIDS will deteriorate as their immune system gradually deteriorates. As time passes, the individual with AIDS will metamorphose physically, emotionally, and psychologically right in the presence of the caregiver, both professionals and family. The cumulative effect of witnessing this process over time and with many clients and family members suffering with AIDS would have an enduring impact on

the caregivers. Death, for them, represents the culmination of bearing witness to a long period of painful, ravaging and disfiguring physical as well as psychological illnesses and difficulties (Pearlman & Mac Ian, 1995).

According to Pearlman and Mac Ian (1995) many could experience vicarious trauma that could be defined as “the transformation that occurs with the therapist (or other trauma workers) as a result of empathic engagement with clients’ trauma, experiences and their sequelae” (p. 558). Perlman and Saakvitne (1995) suggest that this occurs as a result of listening to graphic descriptions of violent events, being exposed to cruelty of people to one another, and participating in traumatic re-enactments. Employing the descriptions by Pearlman and Mac Ian (1995) and Pearlman and Saakvitne (1995), counsellors and therapists exposed to the psychological stress of working with AIDS individuals are subjected to trauma and represent survivors of traumatic life events. According to Pearlman and Mac Ian (1995), vicarious traumatization engenders changes in the way the therapist experiences the self, others, and the world, while its effects permeate the therapist’s inner world and relationships.

Gabriel (1994) argues that most health professionals who care and witness the narratives of those living with and dying from HIV/AIDS experience secondary trauma known as vicarious trauma. This suggests that care giving professionals that experience deaths of group members from HIV/AIDS manifests many of the traumatic stress symptoms observed in those they are caring for. Affected families who give care to HIV/ADS sufferers are also secondarily traumatised in the same way as health care givers.

Nord (1996) adds that professionals involved in the care of HIV/AIDS infected patients experience symptoms. These include death images after the death of one of their patients, survivor’s guilt for their inability to save people, a numbing with the diminished capacity to feel resulting in patterns of withdrawal, apathy, depression, despair, the shattering of the survivor’s basic moral assumptions about the world resulting in patterns of mistrust in human relationships and antagonism toward others, as well as the struggle for

meaning. Furthermore, Nord (1996) argues that the impact of multiple AIDS-related losses and the resultant traumatic stress responses that arise from the ongoing and unrelenting AIDS tragedy, add to caregiver trauma. This further indicates that caregivers including family caregivers do get attached to those they are caring for and consequently get affected by the dynamic of care giving.

Nord (1996) suggests that professionals who survived multiple AIDS-related losses of their clients suffer from symptoms that are consonant with the Diagnostic and Statistical Manual of Mental Disorders-IV (American Psychiatric Association, 1994) in keeping with post-traumatic stress disorder definition. Multiple-loss survivors find death permeating nearly all aspects of their lives and they experience intrusive symptoms (e.g., recurrent and intrusive images), avoidant symptoms (e.g., avoiding reminders of the trauma), and arousal symptoms (e.g., sleep, anger and arousal difficulties) (Nord, 1996). As Nord (1996) focuses on the client's experience of multiple AIDS-related loss, his assertions appear consonant and applicable to mental health professionals including family caregivers who survive loss of clients due to AIDS.

In his study, Silverman (1993) concurs that mental health professionals working with HIV/AIDS patients are likely to experience what he calls HIV/AIDS caregivers stress syndrome typical to signs and symptoms of posttraumatic stress disorder. The responses of individuals working with and having lost clients 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 (Perreault, 1995; Silverman, 1993). This could be associated with what some family member could experience while caring for their members physically deteriorating due to HIV/AIDS.

## **2.7 EMOTIONAL CONSEQUENCES OF HIV/AIDS ON THE FAMILY**

HIV/AIDS has emotional consequences on the family which impacts differently across all generations. The United Nations (2009) states that stigma and discrimination usually attached to the sick person can extend to the whole family in areas where people with HIV are still stigmatized. This will affect social relations, work and educational opportunities, causing emotional distress and isolation. To grandparents, the strain of caregiving, financial difficulties, the pain of coping with the sickness and deaths of children and grandchildren, personal health problems, uncertainty and fears about the future seem to be the key issues. Regarding the adult children, anger, distress, shame, sadness, illness, pain and fear appear to be the main challenges; whereas for grandchildren, anguish and hurt, a lack of understanding, confusion, deprivation, fear, neglect and perhaps abandonment appear to be the major emotional issues. HIV/AIDS also remains a taboo subject in many African countries, and persons with HIV/AIDS and their families may conceal the status of infected family members and thus forego opportunities for community support. Stigmatization of infected persons and affected families further exacerbates the isolation and loneliness of these persons and families. Such are some key social and economic issues which impact the functioning and wellbeing of HIV/AIDS affected families (United Nations, 2009).

## **2.8 THE STRESS OF CARING FOR A FAMILY MEMBER WITH A CHRONIC AILMENT**

Caring for a family member with a chronic condition such as cancer, renal failure, diabetes mellitus, etc., could be an enormous task for the involved families. As much as caring responsibility of an HIV/AIDS infected family member is said to be stressful, other families find caring for a member who is chronically ill due to any other illness beside HIV/AIDS equally stressful (Boss, 2002). It is stated that chronic illnesses such as Alzheimer's disease, cancer, strokes etc. could also be stressful as long as the diagnosis and the prognosis is not well determined or known. The chronicity of the condition and the

continuous demand for care could be stressful and overburdening for caregivers. This also has the potential to deplete family resources and leave an emotional and financial scar on the affected family, especially upon the female members whom the caregiving responsibility is often assigned to (Boss, 2002).

In the initial phase of knowing about the member's illness, the family often use denial to deal with their shock and stress until when eventually resilience sets in to assist the family further. If the situation persists, demands put on caregivers exert pressure that could be stressful for the family and deplete the family coping strategies. Cases of families faced with the long term care of a child with cystic fibrosis indicated that these families experience stress (McCubbin, Patterson, McCubbin, Wilson, & Warwick, 1983; McCubbin et al., 1993). They revealed that these families have the need for the use of recovery factors that facilitate their adaptation and promote family resilience that include the following factors:

- Family support and esteem building. Both parents put efforts to get support from the community and friends and to develop their self-esteem and self-confidence in promoting the child's health;
- Family integration. Both parents put effort to keep the family together and maintain an optimistic outlook in order to promote the child's health and keeping the family together.
- Family recreation orientation, control, and organization. The family's emphasis on an active recreation orientation toward participating in various recreational activities and sporting activities is positively associated with improvements in the child's health over time. Furthermore, the greater the family's emphasis on control and family organization, rules, and procedures, the greater the improvement in the child's health.
- Family optimism and mastery. The greater the family's efforts to maintain a sense of order and optimism, the greater the improvements in the child's health status, Families that also make a commitment to master the medical regimen that carries over into the home environment increase the family's understanding of the medical situation and the adaptation process to the situation (McCubbin & McCubbin, 1993).

## **2.9 FAMILY RESILIENCE**

Family resilience is defined as “the ability to withstand and rebound from adversity” (Walsh, 2002, p130). According to Silliman, (1994), family resilience is described by the Family Resiliency Network as “the capacity of the family to cultivate strengths to positively meet the challenges of life” (p.2). The term is further elucidated by Luther, Cichetti and Becker (2000) who stated that family resilience is the ability to make positive adaptation despite confronting adversity. It is apparent from examining the commonalities of these descriptions that resilience does not exclude tensions and afflictions of life, but rather embraces them with the resources of competence and adaptability, resulting in a positive effect.

Over the past two decades, there has been a shift in the field of family psychology from the traditional pathogenic approach to focusing on family strengths (Hawley & Dehaan, 1996). Focusing on family strengths and resources shifts the perspective of seeing distressed families as damaged to seeing these families as facing challenges, yet possessing the potential to grow stronger as a result of the difficulties they may be facing (Walsh, 2002). Furthermore family resilience according to Hawley (2000) can be described as a process and can be conceptualized as “a pathway a family follows over time in response to a significant stressor or series of stressors” (p106). Various other authors also contributed their definitions of family resilience.

Family resilience research builds on stress, coping and adaptation research (Walsh, 1996). An influential model has been the cognitive appraisal model of stress and coping developed by Lazarus (1991). This model described the adaptive behaviours between a person and their environment which aims at reducing stress levels within the environment by seeking the best adaptation possible. Although influential, this model focused on the individual and not on the family as a unit (Walsh, 1996). Walsh (2003) called for a more systemic view where the family system is looked at as a whole.

According to Walsh (2003), “there are key family processes that mediate the recovery of the family during the crisis situation. These processes enable the family system to rally in times of crisis, to buffer stress, reduce the risk of dysfunction, and support optimal adaptation” (p.3). Whereas previous research has focused on family stress and coping, studies exploring what makes the family system resilient when facing normative changes as well as crises have been slower to emerge (McCubbin, Thompson, Han, & Allen, 1997).

As resilience studies began to emerge, there was a focus on the two components of family resilience, namely family protective factors (factors shaping endurance despite vulnerability), and family recovery factors (factors promoting the ability the family to bounce back). Protective factors are the ongoing development of family strengths so that members are ready when change, challenge, or conflict arises. Protective factors help a family develop flexibility and adaptability. Important family protective factors include family celebrations such as birthdays and holidays, family hardiness (family's internal sense of control, strength and durability) and health, family time and routines, and family traditions. Recovery factors such as connectedness and togetherness are, especially, beneficial in events like coping with a serious illness, an untimely death, the loss of a primary job, or a natural disaster. Family togetherness and a sense that each member is equally important, family and community support, esteem building, participating in family recreation, optimism about life's situations, and a sense of control help families cope and recover (Walsh, 2003).

Previous studies on resilience over the past years have produced ten general resiliency factors. These factors are divided into protective and recovery factors and they include family problem-solving communication, equality, spirituality, flexibility, truthfulness, hope, family hardiness, family time and routine, social support, and health (McCubbin, McCubbin, Thompson, Han, & Allen, 1997). The following is an exploration of these factors.

### **2.9.1 Communication**

Communication encompasses both verbal and nonverbal behaviour by a person, which impacts others around that person (Wills, Blechman, & Namara, 1996). Throughout both normative and non-normative life transitions, communication is necessary amongst family members. Communication patterns within a family help facilitate the achievement of the main family functions (Patterson, 2001a; 2001b). There are two patterns of communication, namely incendiary communication and affirmative communication (McCubbin, McCubbin, Thompson, Han, & Allen, 1997). Incendiary communication is the pattern of communication that involves negative communication styles which tend to make a stressful situation even worse, while affirmative communication shows support and care for family members and facilitates resolution conflict. The latter style of communication aids the family's ability to recover; conversely, poor communication can increase the family's risk (Olson, 1993; McCubbin, Thompson, Han & Allen, 1997; Patterson, 2002b).

Positive communication styles bring clarity during a crisis situation by facilitating open expression and problem solving as a family (Walsh, 1998; 2003a; 2003b). This clarity along with congruent messages fosters effective family functioning (Epstein, Ryan, Bishop, Miller &, 2003).

### **2.9.2 Equality**

Equality is another factor that may contribute to the resilient family. Equality of all family members denotes independence and fosters self-reliance, which enables each member to have the power to make decisions often necessary in a crisis situation. The experience of equality within the family system fosters family adjustment and adaptation (McCubbin, McCubbin, Thompson, Han & Allen, 1997).

### **2.9.3 Spirituality**

According to Silliman (1994) being spiritual involves rising above one's own self-interest, appreciating life and living with a sense of positive purpose. In a crisis, finding meaning amongst the pain helps the family adjust and adapt (Patterson, 2001b). Often explanations and logic do not provide family members with comfort, but finding meaning through a sense of spirituality gives members a sense of strength and aids resilience (McCubbin, McCubbin, Thompson, Han, & Allen, 1997; Werner & Smith, 1992; Yates & Masten, 2004). During times of crisis and difficulty families can look to their religious and cultural traditions as a source of strength, comfort and guidance (Walsh, 1998; 1999). Werner and Smith (1992) found that gaining meaningfulness from spiritual engagement contributes largely to long-term resilience. Turning to God through prayer, faith and participating in church activities when facing adversity are practices which in some families and communities seem to assist in making them feel strengthened. However, in African traditions caring out rituals to appease the ancestors is often seen as a coping mechanism.

Spirituality is an important contributor to feelings of wellbeing and could assist with emotional adjustment. Spirituality among HIV-infected individuals and their families is often perceived as a bridge between hopelessness and meaningfulness in life. Creating meaning and purpose in life more than religious experiences was found to correlate with psychological wellbeing in a large sample of African American men and women with HIV/AIDS (Werner & Smith, 1992).

### **2.9.4 Flexibility**

Flexibility within the family plays an important protective and recovery role in helping the family maintain stability. Walsh (2003a; 2003b) considered flexibility to be a vital component in the process of resilience. Olson (1993) used the term adaptability which is defined as “the ability of marital or family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress” (p. 21). When a family

has flexibility they are able to adjust their pattern of functioning to help them cope in times of difficulty (McCubbin, McCubbin, Thompson, Han & Allen, 1997). While too much change can contribute towards family instability, it is necessary to find a balance between change and stability if flexibility is to aid the resilience of a family (Patterson, 2000).

Minuchin (1974) indicates that families must constantly adapt to change – change resulting from contact with problems and stressors outside the family, change resulting from transitional or developmental points in the family life cycle, or change from idiosyncratic problems (such as a child being born with a disability). Most families are sufficiently flexible to adjust to these changes. Dysfunctional families are those families who in the face of stress increase the rigidity of their transactional patterns and boundaries, and avoid or resist any exploration of alternatives.

Barnhill (1979) also identifies flexibility (in contrast to rigidity) as an important component of healthy family systems. Gantman (1980) stated that families are optimally conceived of as highly flexible systems which respond spontaneously and are open to growth. Structure exists but is subordinate to function or process. Trivette, Dunst, Deal, Hamer, and Propst (1990) indicate that strong families are characterized by flexibility and adaptability in the roles necessary to procure resources to meet needs. In addition, Otto (1963, in H.I. McCubbin & McCubbin, 1992) concur that flexibility in performing family roles is one of the dimensions of strong families.

Olson's Circumplex Model, which was mentioned previously in connection with its plotting of degrees of cohesion (from disengaged to enmeshed) on the horizontal axis, also plots adaptability on the vertical axis (Olson, 1988). Adaptability ranges from extremely high (chaotic), moderately high (flexible), moderately low (structured), to extremely low (rigid). According to Olson et al., (1988) flexibility in Circumplex Model is defined as the ability of the marital or family system to change its power structure, role relationships, and

relationship rules in response to situational and developmental needs. Olson et al., (1983) however, found that cohesive/connected families that are flexible are more resilient than cohesive structured families, but separated families that are structured are more resilient than separated flexible families. Therefore, the researchers conclude that family flexibility, by itself, is not a critical factor in family vulnerability to stress and its resilience in response to demands.

#### **2.9.5 Truthfulness**

Truthfulness amongst the family members and from other environments (e.g. social, medical) is essential in helping the families adapt. Truthfulness enables the family to gain information from which they can assess the situation and from which they can then guide their steps (McCubbin, McCubbin, Thompson, Han & Allen, 1997).

#### **2.9.6 Hope**

Hope is another protective and recovery factor that aids the family in the adaptation process. Crises are often paired with a sense of helplessness. It is important that amidst this helplessness the family is able to cling to a sense of hope. Seligman (1990) used the concept of “learned optimism” to explain when people begin to believe that their efforts can work. McCubbin, McCubbin, Thompson, Han and Allen, (1997) explained that hope means that the family has “wishes or desires that are accompanied by a confident expectation of their fulfillment” (p. 14). Christian families often put their hope in God through faith and prayer believing that God will redeem the family through their difficult times of caring for the diseased family member. Having a sense of meaning and spirituality that rises above one’s painful circumstances allows for a sense of hope despite uncertainty (Walsh, 1998).

### **2.9.7 Family hardness**

Family hardness is a resiliency factor that buffers against the effects of stress on health (Svavarsdottir, McCubbin & Kane, 2000). Having a sense of control over the end result of the challenges the family is experiencing is referred to as family hardness. It involves the family pulling together as a unit to handle the problem together and reframing the crisis as a challenge, which ultimately assist the family to adapt (McCubbin, McCubbin, Thompson, Han & Allen, 1997). It also involves taking an active stance in adapting to stressful situations (Svavarsdottir, McCubbin & Kane, 2000).

According to McCubbin et al. (1997) and McCubbin et al., (1996), hardness is one of the key resilience factors that forms a central part of the Resiliency Model, which is the theory underpinning the present study. McCubbin et al., (1996) further view family hardness at various levels which include looking at commitment to the family as a unit, the manner in which the family views the stressor as manageable, and lastly the sense of the family feeling more or less in control of their lives despite the presence of adversity. Hardiness refers to the resistance offered when confronted by stressors, particularly the steeling type of resistance offered. The presence of hardness as a resilience factor is supported in theory.

### **2.9.8 Family time and routines**

Family time and routines are also some of the important factors that add to family resilience in times of adversity. They often help the family during a crisis to maintain a sense of stability and continuity. Family time and routines can involve for example, sharing family meals together, spending an afternoon together, or simply sharing a cup of tea before bedtime. According to McCubbin and McCubbin (1988) such routines play an important role in creating continuity and stability in family life. Spending time together and having common routines help the family system create a sense of predictability and togetherness (McCubbin, McCubbin, Thompson, Han & Allen, 1997). Family time together and routines are also considered reliable

indicators of family integration and stability (McCubbin, Thompson & McCubbin, 1996). McCubbin, Thompson and McCubbin, (1996) emphasized the many advantages of family patterns of stability when they stated that these patterns “allow family units to bridge generations, establish continuity in the present and in the midst of disruptions, and build a solid foundation of interpersonal supports needed to negotiate major transitions and transformations” (p. 358).

Crouter, Head, McHale and Tucker (2004) argued that in most families dinner time appears to be one of the main activities families (especially black families) share a meal together followed by television viewing. Time spent as a family unit has been shown to decrease risky behaviour significantly in teenaged children (Milkie, Mattingly, Nomaguchi, Bianchi, & Robinson, 2004). Nevertheless, family time appears to be dwindling as a result of increased parental demands and responsibilities; as well as teenagers' excessive use of social media and internet which has become of more use to them instead of spending time with families. The situation could be worsened by the fact that most parents including mothers are working and others even work far from home making coming home daily almost impossible. They spend insufficient time with their children, a factor which contributes to drifting the family apart.

### **2.9.9 Social support**

Social support is one of the protective and recovery factors most families use when facing crisis situations. The family draws on its supportive relationships to help during its time of crisis (Walsh, 1996; 2003a). There are five dimensions of social support, namely emotional support (e.g. caring), esteem support (e.g. affirming value), network support (e.g. knowing that there is a group of people to whom the family is both responsible and from which the family can draw on as a resource), appraisal support (e.g. giving family members a sense of boundary), and altruistic support (e.g. giving of oneself for the gain of others) (McCubbin, McCubbin, Thompson, Han & Allen, 1997). The value of social support is explained by Wills, Blechman and McNamara (1996) when they stated that, “interpersonal relationships enhance adaptation

through provision of supportive functions that are of direct or indirect assistance for the coping process" (p. 109).

There are factors such as protective factors and recovery factors that indicate resilience. Protective factors are the on-going development of family strengths which indicate that members are ready when change, challenge, or conflicts arise. These factors help a family develop flexibility and adaptability. Important family protective factors include family celebrations such as birthdays and holidays, family hardiness and health, family time and routines, and family traditions (Shor, Roelfs & Yoge, 2013).

The recovery factors are especially beneficial in events like coping with a serious illness, an untimely death, the loss of a primary job, or a natural disaster. Family togetherness and a sense that each member is equally important, family and community support, esteem building, participating in family recreation, optimism about life's situations, and a sense of control help families cope and recover. When the family faces challenges according to Shor, Roelfs and Yoge, (2013) support from family members seems more beneficial than support provided by friends, and moderate levels of such support may be enough to achieve positive results.

Social support for patients with HIV/AIDS and their families has shown a strong potential to influence resilience and quality of life. There are types of major components of social support namely, emotional, tangible, and informational support. Distinction among the different types of social support is relevant, since their functions may not be necessarily interchangeable. Emotionally sustaining functions of social support, which serve to fulfill and gratify the needs of people for nurturance, belonging, and alliance, are well recognized to buffer stress in non-HIV settings. Social support is also seen as a buffer for and a factor that moderates the adverse health effects of stress and loneliness by providing an active coping assistance and by fostering feelings of intimacy, attachment, control, self-worth, self-competence, and emotional sustenance (Uchino, 2006; Umberson, Crosnoe, Reczek, 2010).

Emotionally sustaining support was considered more desirable and was more often used than other forms of support. In another study, however, satisfaction with tangible or informational support was a stronger predictor of better resilience and quality of life than was satisfaction with emotional support. This is supported by the study conducted on HIV infected gay men in San Francisco, where informational support was considered particularly critical for patients experiencing HIV-related symptoms (Umberson, Crosnoe & Reczek, 2010).

### **2.9.10 Health**

Health is one of the resilient, protective and recovery factors. The physical and emotional health of family members promotes resilience in the family unit and protects the family system against vulnerability. If a family member is not healthy, this can contribute towards making the family unit more vulnerable and therefore, susceptible to physical challenges such as stress (McCubbin, McCubbin, Thompson, Han & Allen, 1997). Levels of stress, anxiety and depression were found to be high among caregivers caring for gay partners with HIV/AIDS as compared to control caregivers (Kocsis, Church & Green 1991); Irving, Bor & Catalan, 1995). Furthermore, the study conducted by Mc Shane, Bumbalo and Pats, (1994) also indicated that parents and siblings of people ailing from HIV/AIDS were found to be having high levels of overall distress and also scored high on symptom dimensions and clinically discrete symptoms as compared to controls.

## **2.10 CHARACTERISTICS OF RESILIENT FAMILIES**

Families rely on certain factors to navigate through their stress of caring for ailing members. These include specific characteristics such as the following:

- *Commitment* which is a balance of dedication and accountability. It includes actions that demonstrate loyalty, determination to work things out together, and sacrifice for the benefit of all.
- *Cohesion* which indicates the degree of family togetherness with emphasis

on respect for each person's uniqueness, and emotional closeness and practical dependence on each other.

- *Adaptability* which involves balancing family stability with flexibility and skills developed for coping with stress.
- *Communication* which involves respectful listening and speaking skills, including openness, clarity, accuracy, honesty, and mutuality (Epstein, Ryan, Bishop, Miller & Keitner, 2003).
- *Spirituality* which includes the capacity for going beyond self-interest, living with a positive purpose, and reverencing life. In families it may mean having shared purpose and values, often in the context of religious faith and practising what you preach (Yates & Masten, 2004).
- *Connectedness* which is the capacity for contributing to and receiving from the extended family, the community, or the nation. It is an attitude of service and belonging to a larger whole (McCubbin et al., 1997).
- *Resource management* which involves the competent and coordinated use of time, money, and the handling of stress.

## **2.11 COPING AND FACTORS THAT INFLUENCE COPING IN STRESSFUL SITUATIONS**

Coping seems to be embodied within the resilient concept. However, unlike resilience the family becomes resistant to stressful events and goes back to the previous level of functioning even to higher levels of functioning post the event. On the other hand, during the coping process the family seems to undergo changes and develop even new strategies of handling the situation. Folkman and Lazarus (1980) defined coping as the cognitive and behavioural efforts made by people to master, tolerate or reduce external and internal demands that are caused by stressful transactions.

Any situation people have to deal with, that places high demand on both internal and external resources of the affected people could consequently push them over the edge. Folkman in Folkman and Lazarus (1985) further added that coping alludes to efforts to manage demands despite the success of those efforts. Coping is, therefore, a process of executing a potential

response or what can be described as secondary appraisal, to a stressful situation, after people have had appraisal of the threat to themselves (Carver, Scheier & Weintraub, 1989).

According to Bor, du Plessis and Russell (2004), in stressful situations family members recognize different mechanisms to cope with the HIV/AIDS status of members. Some families used denial of the reality of the situation by not thinking of the implications of the patient's future illness, or by occupying themselves with work or social activities and using humour to reduce the intensity.

There are several factors which according to Bor et al., (2004) appeared to influence the way that family members cope with HIV/AIDS affecting their lives, such as the infected members' own level of coping, their own personalities and coping styles and the meaning that death had for them. Family members cope better if the infected members could communicate openly about their diagnosis and implications for the future. However, on other occasions open expression of the patient's feelings, such as sadness and low mood, could also make it difficult to cope as well as the suffering or imagined suffering of the member, as this could make the HIV diagnosis more real and impossible to deal with.

The positive attitude of some of the infected member makes a difference to the family member's own coping. Family members generally expressed admiration for the sufferers who lived life to the full and refused to let HIV/AIDS determine all aspects of their lives. Furthermore, Bor et al., (2004) discovered that family members who had experience of people dying appeared to cope better with the implications of the patient's future illness. Those family members who more easily accepted that death is a part of life seemed to cope better with the fear of the unknown and the insecurity of HIV. Several family members indicated that feeling impotent in the face of advancing illness made it difficult to cope (Bor et al., 2004).

Perceptions and attitudes also contributed to adjusting and coping with HIV/AIDS. Those families who considered themselves to be strong and accepting said that they felt that they coped better with the status and illness of their family member. Optimism in other families helps them to cope with most adverse situations. Focusing on the positive outcomes help families cope with adversity. Thinking about the patient either dying or suffering made coping harder. Some family members also indicated that their own lack of knowledge about HIV/AIDS in certain families makes it more difficult to accept the infected family member and implications of his illness (Bor et al., 2004).

## **2.12 THE FUNCTIONS AND DIMENSIONS OF COPING**

While looking at the process of coping, it is also pertinent that we determine what the functions of coping are. According to Folkman and Lazarus (1980), coping has two main functions. First, emotion-focused coping, which refers to the ability to regulate one's distress experienced emotionally from a disturbing event and second, problem-focused coping, which involves the actual efforts aimed at changing the person-environment relationship in order to elicit a more "manageable" relationship (Folkman & Lazarus, 1980).

According to Carver, Scheier and Weintraub (1989) there are certain key elements or dimensions involved in coping, namely active coping, which refers to the process of initiating some form of active effort to try and remove or alleviate the effects of the stressor; planning that involves cognitive effort at handling the stressful situation; suppression of competing activities, which is about ignoring other activities in order to deal with the stressor; restraint coping that refers to containing oneself from reacting, until it is appropriate to do so, in an attempt to deal with stressor; seeking social support for instrumental reasons that focuses on the individual actually seeking form of advice and information or assistance from others around him/her, where individuals will want specific information about for example about how to deal with financial problems.

On the other hand, seeking social support for emotional reasons is about gaining moral support, sympathy and understanding from others, in relation to the stressful situation. In this case, the distressed individual wants someone to listen and empathize with him/her. Positive re-interpretation and growth, also referred to as positive reappraisal, is aimed at managing distressful emotions, instead of the stressor itself. Acceptance involves accepting the reality of the situation in the attempt to deal with it. The opposite of acceptance is denial, which refers to refusal to acknowledge the reality of the stressor. Denial is often present in the way suicidal individuals are trying to cope (Carver et al., 1989).

Turning to religion is another way of dealing with a stressful situation. Focus on and venting of emotions refers to the individual's ability to focus on the distress and be able to express feelings of upset that are experienced relative to the stressor. Behavioural disengagement is actually a form of helplessness, but involves a reduction of efforts to deal with the stressor. Mental disengagement serves to distract the families from focusing too much on the stressor. Finally, alcohol-drug disengagement concerns those members who choose to rather engage in the usage of alcohol or drugs in order to deal with the stressor (Carver et al., 1989).

The dimensions which can be grouped as problem focused attempts include active coping; planning; suppression of completing activities; restraint coping and seeking social support for instrumental reasons. Emotion-focused attempts involved seeking social support for emotional reasons, positive re-interpretation and growth, acceptance, turning to religion, focusing on venting of emotions, denial, behavioural disengagement, mental disengagement and alcohol-drugs disengagement and attempts by the people to regulate or control their emotions and distress levels in order to deal with the stressor (Carver et al., 1989).

It is therefore, clear that inability to gather social support in order to overcome life difficulties including HIV/AIDS in the family may consequently also lead to failed coping and result in negative primary and secondary appraisal as well as family disintegration.

## **2.13 THE PSYCHOLOGICAL IMPACT OF HIV/AIDS IN THE FAMILY AND ITS INFLUENCE ON SOCIAL SUPPORT**

Systems of social support for family members with HIV/AIDS may differ from those found with people suffering from other potentially life-threatening chronic illnesses such as diabetes mellitus, hypertension, cancers and chronic diseases. These include the unique way in which HIV can be transmitted between people and the social stigma attached and prejudice that accompanies infection with HIV, especially among intravenous drug-users and gay men (Crandall & Coleman, 1992). It has already been observed that, while traditionally, biological family members provide practical, emotional and social support during a time of illness, this typical pattern of support is not necessarily available when the sufferer concerned is infected with HIV/AIDS (Bor & Elford, 1998). Research has highlighted the fact that HIV infects individuals and simultaneously affects a whole network of significant relationships, especially those who provide the majority of the day-to-day social support such as family members and caregivers (Bor & du Plessis, 1997; Leask, Elford, Bor, Miller & Johnson, 1997).

However, there have been few studies that have examined the nature of the experience from the perspective of the caregivers. The study conducted by Raphael, Kelly, Dunne and Greig (1990) is one such example. The study examined the distress experienced by volunteers and health professionals who were working with HIV patients and discovered that 37 per cent of participants had measurable symptoms of psychological stress (e.g. depression and anxiety) and 14 per cent had severe symptoms (Raphael et al., 1990). Similar results were reported by Guinan, McCallum, Painter, Dykes, & Gold, (1991) who found that 37 percent of the HIV volunteer workers

whom they studied could be classified as having some form of definable mental illness, of which 24 percent showed signs indicative of a severe mental disorder. Kocsis and colleagues (1991) studied the carers of gay men with AIDS and found that the majority of carers (70 per cent) were involved in a gay relationship with the patient, and that levels of depression and anxiety were raised in the carers compared to controls.

Irving, Bor and Catalan (1995) investigated the psychological problems of thirty-eight gay men, some themselves infected with HIV, who were the primary carers of a partner with AIDS. They found that the participants reported high levels of both global and AIDS-specific psychological stress. The levels of stress being of such intensity that most in their sample impact of disclosure of HIV 169 were probably suffering from significant psychiatric problems. While the design of that study precluded a definitive causal analysis, the results suggest that providing care and support for a lover or partner with AIDS may have an adverse effect on the psychological health of caregivers.

The psychological health of both AIDS patients (PWA) and their families was assessed in another study (Mc Shane, Bumbalo & Pats, 1994). Parents, siblings and PWAs were all found to have higher levels of overall distress, and also scored higher on symptom dimensions and clinically discrete symptom indicators as compared to normative controls. It would appear that the caregiver role is often both stressful and debilitating. In serodiscordant relationships, where one partner is infected with HIV and the other is HIV negative, care-giving may be further complicated by the risk of transmission during sexual intercourse. In a qualitative study of a small sample of men in such relationships, Palmer and Bor (2001) found that some negative partners put themselves at risk of becoming infected with HIV. Surprisingly, the risk was greater from sexual partners outside of the primary relationship than between the couple. How couples adjust to illness is a topic that has not been extensively studied (Rolland, 1994), although it is reasonable to assume that where both partners are ill or infected, the dynamics of care-giving become even more complex (Bor et al., 2004).

## **2.14 EMOTIONAL REACTIONS OF FAMILY MEMBERS TO THE DISCLOSURE OF HIV STATUS OF THE FAMILY MEMBER**

Disclosure of the HIV status of a family member has always been viewed as the most challenging event both for the infected and the affected members of the family, especially discovering the status when the infected member is already at the advanced stage of HIV/AIDS. A range of initial reactions were reported by the family members to the HIV disclosure event. According to Bor et al., (2004), the majority of people and families are often shocked upon discovering of the HIV/AIDS status their members. Family members often react with shock, sadness, devastation, fear, confusion due to a lack of HIV knowledge, as well as disappointment due to the perceived sudden shortened life expectancy of the infected member. Knowing the HIV status of a family member also seems to have the ability to change a number of things in the family including how they relate to each other. Whereas the relationship was previously based more on friendship, for example, it often changes to more of a caring role after HIV disclosure especially, if the infected member is already in a progressed state. However, increased knowledge about HIV, adaptation and adjustment over time seemed to moderate the first reaction to the HIV disclosure (Bor et al., 2004).

After discovering about the HIV status of the family member, some members often express the need to know more about HIV/AIDS, talking openly within the family and with the patient as a means of obtaining information about his/her health and treatment. Talking is often perceived as a way of relieving the burden of knowing the HIV status of the family member (Bor et. al., 2004). At the same time, considering unique ways in which Africans mostly deal with the issue of that nature, family secrecy is likely to be the common way of dealing with a family member's HIV status and its potential stigma on the family. This could be regarded as the way in which the family protects the infected member as well as its own integrity from disintegrating.

## **2.15 STAGES OF HIV PROGRESSION**

According UNAIDS (2007) and Foundation for Professional Development (2011), the progression of the HIV/AIDS disease passes through a number of stages which include the following:

### **2.15.1 Acute HIV infection (the window period)**

Here the individual has been infected with HIV but the body has not yet started producing antibodies to fight the HIV. The HIV therefore, is able to develop rapidly. The Viral Load increases very rapidly and the CD4 count declines rapidly during this period. This time-during which people can be highly infectious and yet unaware of their condition- is known as the “window period”.

### **2.15.2 Seroconversion**

A number of weeks after infection with HIV (usually between 6 to 12 weeks, but for a few people the period can be 6 months) the immune system starts to produce many antibodies to fight the HIV. During this stage some people have a “glandular fever” like illness (fever, rash, joint pains and enlarged lymph nodes). The immune system is very successful in clearing HIV out of the system and during this stage the Viral Load declines and the CD4 count recovers.

### **2.15.3 HIV infection before the onset of symptoms**

In adults, there is often a long silent period of HIV infection before the disease progresses to AIDS. A person infected with HIV may have no symptoms up to ten years or more. The vast majority of HIV-infected children are infected during childbirth. The period without symptoms is shorter in children, with only a few infants becoming ill in the first few weeks of life. Most children start to become ill before 2 years; however, a few remain well for several years.

#### **2.15.4 Progression from HIV infection to HIV-related disease and AIDS**

Almost all (if not all) HIV-infected people will ultimately develop HIV-related disease and AIDS. This progression depends on the type and strain of the virus and certain host characteristics. Factors that may cause faster progression include age less than 5 years, or over 40 years, other infections and possibly genetic (hereditary) factors. HIV infects both the central and peripheral nervous system early in the course of infection. This causes a variety of neurological and neuropsychiatric conditions. Also extremely important is whether the immune system is protected.

Changing lifestyle to protect the immune system will slow the process of the decline of the immune system. As HIV infection progresses and immunity declines, people become more susceptible to opportunistic infections. In this stage the infected family member might experience opportunistic infections such as Tuberculosis, other sexually transmitted diseases, Septicemia, Pneumonia (usually *Pneumocystis Carinii*), recurrent fungal infections of the skin, mouth and throat, unexplained fever, meningitis, chronic diarrhea with weight loss (often known as a slim disease), cancers (e.g. Kaposi Sarcoma) and many more (UNAIDS, 2008).

#### **2.16 CONCLUSION**

This chapter explored various studies conducted on family stress, caregiving stress and HIV/AIDS caregiver syndrome. It also provided studies on family resilience and the HIV/AIDS crisis in Southern Africa. Insights on the stages of HIV/AIDS progression, the emotional reaction of family members to the disclosure of HIV status of one of their members and the eventual physical progression into AIDS were explored. The chapter also highlighted the impact of HIV/AIDS on the family and on social support towards members physically deteriorating due to HIV/AIDS. The next chapter will outline the theoretical formulation of the study.

## **CHAPTER 3**

### **THEORETICAL FRAMEWORK**

#### **3.1 INTRODUCTION**

This section of the study will present an outline of the theoretical models within which the study is based. This includes the operational definitions, resiliency model of family stress, adjustment and adaptation as well as the family stress theory.

#### **3.2 OPERATIONAL DEFINITIONS**

- Family resilience is a concept that describes how families adapt to stress and bounce back from adversity.
- Resilience has been described as the human capacity to face, overcome and be strengthened by or even transformed by the adversities of life, the universal capacity which allows a person, group or community to prevent, minimize or overcome the damaging effects of adversity, the ability to bounce back, the ability to cope with life's adversities.
- Family is defined as the group of people living together for the benefit and development of each member and the group as a whole.
- Human Immunodeficiency Virus (HIV) is a human virus that causes AIDS.
- Acquired Immune Deficiency Syndrome (AIDS) is a transmissible retroviral disease due to infection with human immunodeficiency virus (HIV), manifested in severe cases as profound depression of the immune system.
- Family caregiver is a family member representing the rest of family caregivers caring for family member/s infected and physically deteriorating due to HIV/AIDS related illnesses. This includes parents, children, grand parents and relatives.
- Family crisis refers to a state of imbalance, disharmony and disorganization in the family system following trauma within the family.

- Family stress refers to psychological demands put on family due to the challenge the family is facing.
- Stress is the outcome resulting from an imbalance between demands and resources which occur when pressure exceeds one's coping ability.
- Families caring for members physically deteriorating due to HIV/AIDS will also be called HIV/AIDS affected families.
- Families caring for members ailing due to any other chronic condition will also be known as families affected by any other chronic condition.

### **3.3 THEORETICAL FRAMEWORK**

This part of the study focuses on the theoretical models upon which the study is conceptualized. Resiliency Model of Family Stress, Adjustment and Adaptation which incorporates the Family Stress Theory were used as the basis of this research. These models will be discussed in detail in the coming sections.

#### **3.3.1 The Resiliency Model of Family Stress, Adjustment and Adaptation**

Resiliency model of Family Stress, Adjustment and Adaptation was developed by McCubbin and McCubbin (2001) as an extension of the ABCX crisis model which focused its attention on the built up of crisis and ends at the point where crisis arises. On the other hand, Resiliency Model of Family Stress, Adjustment and Adaptation is also known as the double ABCX model. Unlike the ABCX crisis model, the double ABCX model focuses on the pre-crisis and post crisis occurrences. According to the model A stands for the event, B represents family resources, C the definition the family has on the event and X is the actual crisis situation (McCubbin & Patterson, 1993).

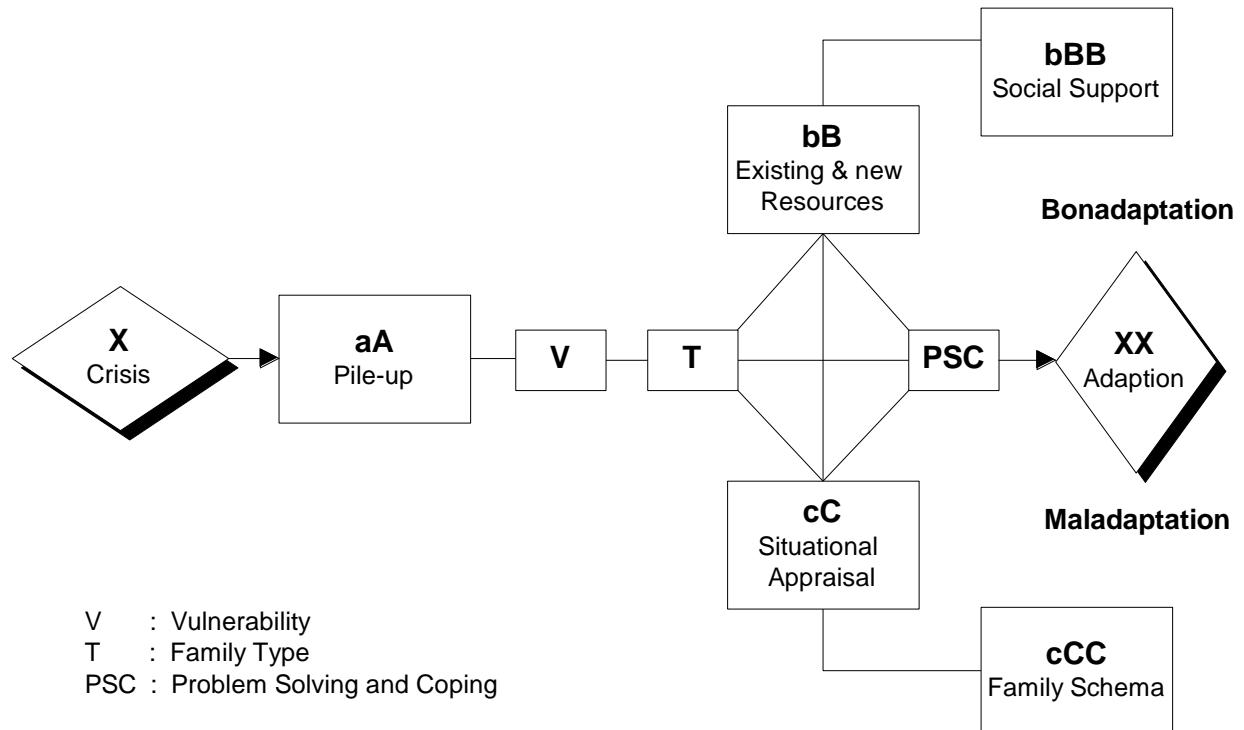
Resilience model of Family Stress, Adjustment and Adaptation maintains that the family faces a crisis situation (X), which in this case is the physical deterioration of the family member due to HIV/AIDS. The existence of this crisis in the family piles up (Aa) demands of caring for this member therefore,

making the family vulnerable to stress. Vulnerability (V) of the family, on the other hand, depends on the family typology (T). Type of the family determines family problem solving coping (PSC) ability as well. That is also influenced in two ways by the existing (B<sub>b</sub>) and new resources within the family which, in turn, is influenced by the support (B<sub>bb</sub>) the family gets during the time of dealing with the crisis of caring and coping. This strengthens the family and allows the development of new and existing family resources.

Family type is also affected by the way the family assesses or appraises (Cc) the situation which is in turn is affected by family make. Family type and problem solving coping abilities determine the type of adaptation (XX). This will either be bonadaptation or maladaptation. These are the resilience factors which appear to play a vital role in moderating stress caring in the family

The aim of the Resiliency Model of Family Stress, Adjustment and Adaptation is to understand and explain the reason why some families recover and others remain at risk and even deteriorate under similar situations (McCubbin & McCubbin, 1993, 2001). The Resiliency Model of Family Stress, Adjustment and Adaptation consists of two phases: the adjustment phase and the adaptation phase (McCubbin & McCubbin, 1993, 2001; McCubbin, McCubbin, Thompson, Han, & Allen, 1997).

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



### 3.3.1.1 The adjustment phase

This first phase of adjustment consists of different variables which interact and ultimately shape the outcome of the family. The various interacting variables which influence the outcome of the family will now be explained. As a result of a pile-up of family strains, the family becomes vulnerable. Vulnerability is defined by McCubbin and McCubbin (1993) as the interpersonal and organizational condition of the family system. A family's vulnerability may be high or low. This depends on the pile-up of the demands on or within the family, and the normal stressor and demands associated with the stage of the family in the life cycle (McCubbin & McCubbin, 1993).

The stressor the family faces impacts on the vulnerable state of the family. A stressor is “a demand placed on the family that produces, or has the potential of producing changes in the family system” (McCubbin & McCubbin, 2001, p.

17). The impact that the stressor has on the family is partially determined by the severity of the stressor. Severity is determined by how much the stressor jeopardizes functioning, resources, and stability of the family (McCubbin, 1990; McCubbin & McCubbin, 2001). In turn, the vulnerability of the family interacts with the type of the family typologies because they play a pivotal role in ensuring family harmony and balance.

Stress creates pressure of some kind of adjustment. This can result in either distress (where the stress becomes unmanageable and the family views the imbalance as negative), or eustress (where the tension is viewed as positive and challenges the family in a way that they appreciate the resulting change) (McCubbin & Patterson, 1983). Outcomes of the adjustment phase are on a continuum ranging from bonadjustment which implies maintenance of family patterns, versus maladjustment, which accumulates into a family crisis and ultimately changes the patterns of functioning within the family (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996).

### **3.3.1.2      The adaptation phase**

The adaptation phase of the Resiliency Model of Family Stress, Adjustment and Adaptation includes interacting elements on the path towards a continuum of adaptation. Adaptation ranges from bonadaptation versus maladaptation. A successful family adaptation is referred to as bonadaptation and unsuccessful adaptation is called maladaptation (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996). Throughout this process the family introduces changes aimed at restoring its harmony and balance to both the family and its external environment (McCubbin & McCubbin, 2001; McCubbin, Thompson, & McCubbin, 1996). The adaptation phase describes what happens in families in a maladjusted crisis situation when adjustment fails to significantly incorporate a crisis situation into harmonious family functioning. Unsuccessful adaptation brings about the cyclical nature of the model in that the cycle starts again, with changes in patterns of functioning, and recycles through the family processes of adaptation. The level of family adaptation is determined by the interaction of three distinct but interacting

factors, namely new patterns of functioning, family resources and family appraisal of the stressor.

### **3.3.2 Family Stress Theory**

Family stress theory provides ways of viewing the efforts of the family over time to adapt to multiple stressors through using family resources and perceptual factors as coping process aimed at achieving family balance. A family situation addresses multiple demands and changes, not a single stressor (McCubbin & Petterson, 1981). Secondary stressors such as role change, responsibility and family care giving demands emerge from primary stressors. This leads to chronic strain, causing build ups of unresolved stressors and to undesirable characteristics in the family environment and family system (Figley & McCubbin, 1983).

Family stress theory suggests that stress may be perceived or experienced both as a crisis and a challenge to overcome (Figley, 1989). The family may perceive the stressor as having caused a crisis or it may accept it and see it as a challenge. The latter implies that over time, family engaged in a constructive effort to manage the stressor will redefine their total situation (McCubbin & Petterson, 1981). This implies that if the family perceives the HIV/AIDS sickness of a member as a crisis, possibility of recovery is minimal, unlike if they perceive it as a challenge where recovery is optimal.

Family stress theory also emphasizes the need for intervention to assess whether the family behaviour is functional or non-functional, and ways of committing all family members to working together in the care of the sick member (McCubbin & Petterson, 1981). Although dynamics in one's life and family situation could lead to increased stress levels, predisposing them to physical illness, Roth (1989) discovered that there are certain factors that could moderate these effects. Increased fitness and individual or family hardiness, as a matter of fact, work as a buffer defense to avoid individual or family disintegration that could lead to either physical illness or family dysfunction (Baron & Byrne, 1991).

Family stress theory also studies normative family transitions and adaptation to major life changes and illness which is based on the central role that family strength and capabilities play in understanding and explaining psychological and behavioural outcomes (Figley, 1989). According to McCubbin and McCubbin (1993) in family stress theory, the family is viewed as encountering hardships and changes as an inevitable part of family life over the life cycle. According to this theory, stress may be perceived as or experienced as a crisis and a challenge to be overcome by the family (Lim & Zebrack, 2004). However, each family may perceive the stressor in its own unique way.

McCubbin and Peterson (1981) mention that family stress theory provides a way of viewing the family's efforts over time to adapt to multiple stressors through using family resources as a coping process aimed at achieving family balance. Figley and McCubbin (1983) believe that the family goes through multiple changes and demands simultaneously. Secondary stressors such as role change, responsibility, and caregiving demands emerge from primary stressors and the strain may be difficult for the family to resolve, thus leading to chronic strain, which in turn causes a pileup of unresolved stressors.

### **3.4 CONCLUSION**

The chapter outlined the theoretical models which underpin the concept of family stress and dysfunction in families facing the burden of caring for their members. It based the arguments on the Mc Cubbin's Resiliency Model of Family Stress, Adjustment and Adaptation which consists of the adjustment phase and adaptation phase. The model further explains how families cope with stress by mobilizing adjustment processes and adapting to the demands; thus bouncing back irrespective of their stressful experiences. The stress theory which is also embedded within Mc Cubbin's Resiliency Model of Family Stress, Adjustment and Adaptation explores how the family perceives and experiences stress; either as a crisis or a challenge. This determines the ultimate outcome of bonadaptation or maladaptation. The next chapter will address the African cultural contextualization of family stress and HIV/AIDS. Families are overly impacted by the increasing numbers of members who are

sick because of HIV/AIDS. It will also explore the perceptions and how the family is overburdened by caring for members with HIV/AIDS.

## **CHAPTER 4**

### **CULTURAL CONTEXTUALIZATION OF FAMILY LIFE AND HIV/AIDS**

#### **4.1 INTRODUCTION**

The previous chapter explored the theoretical background of family stress and dysfunction as well as the resilience, including the different factors, characteristics of resilient family, coping strategies as well as the different stages of HIV/AIDS progression. However, family and culture plays an important role in the way people within it deal with the stress of HIV/AIDS. This section will discuss the impact of HIV/AIDS on families, African cultural contextualization of family life, cultural perceptions of HIV/AIDS, family structures and functions affected by HIV/AIDS and family and household responses to HIV/AIDS.

According to Patel (1995), the family in South Africa has always been viewed as an adaptive and vibrant institution that went through a series of adversities and came out resilient. It is this resilient nature of the family that made it possible for these families to respond creatively to the historic challenges such as colonialism, apartheid policies, political turmoil, large-scale urbanization, and economic difficulty. However, in the face of the detrimental impact of HIV and AIDS, the question arises as to whether the family, as a network of care and integral social resource in society, will be able to live up to this challenge. Patel (1995) and Crother (2001) add that although HIV and AIDS may impact on individual and family life indiscriminately, regardless of race, class, gender and age, the epidemic has, however, been spreading with consequential speed among black heterosexuals of both sexes, thus effecting African family life extensively.

## **4.2 THE BOND WITHIN EXTENDED AFRICAN FAMILY STRUCTURE**

In Western cultures the strongest bond is within the nuclear family, meaning the parents and siblings. In African family perspective the family is defined in terms of the extended family. For Africans the institution of family for a long time has been central in the provision of its members' needs, safety and survival. The extended family system was the most important indigenous African institution, with many African families being characterized by large numbers of member with close kinship ties. The family provides a sense of belonging, care, security and social support to its people. Therefore, strong bonds develop with the extended family and tribe (Triandis, 1994). Close relationships are formed and maintained with the extended family members such as uncles, aunts, cousins and grandparents. Informal adoption practices where extended family members care for an individual also testify to the existence of such strong bonds.

The support that family members get from these close bonds indicates what is termed as "in-group" status. People readily cooperate and even sacrifice themselves for one another in such in-groups. On the other hand, people may be willing to fight with, oppose or be indifferent to individuals not considered part of their in-group. This is then referred to as their "out-group" (Triandis, 1994). The distinction is necessary in order to understand why social support that Africans get from their extended family and tribe members, outside the nuclear family, is considered to be of crucial importance.

In African cultures (especially, in rural areas), neighbours are also very important collective entities and can be considered part of the extended support network of an individual, while in Western culture (mostly urbanized), people do not even know or have interest in the affairs of their neighbours. According to Nisbet (1996) when family members are facing hardships which have the potential to destroy them, they use family support systems to cope

and to be resilient. This links to the collectivistic nature and in-group theory of African families upon which it is based.

Maris (1981) is also of the opinion that support networks extending beyond the family have protective value. Such supportive networks may include friends and other community networks such as the church or school.

#### **4.3 THE IMPACT OF HIV/AIDS ON FAMILIES, COMMUNITIES AND THE SOCIETY**

The family unit is the basic building block of most societies and the impact on the family impacts on communities passes through to the general society. Studies have shown that the impact of HIV/AIDS on poor families is negative and often severe (Johnson, 2010). Equally it is clear that the way and the degree to which the epidemic impacts differs from one family to another. Some of the ways in which the family is impacted are:

- The cost of care (both actual cost and time spent on care) including the cost of transport.
- Sickness and funeral costs.
- Loss of income through absenteeism, illness, medical boarding or dismissal of both the infected and the caregiver.
- Support for other families directly affected by the epidemic through, for example, caring for ill family members.
- Taking care of children whose parents are ill or who have died.

HIV/AIDS can also erode family support systems where, for example, the extended family is less able to be supportive due to its being damaged by the epidemic. Government services may also be compromised through, for example, the public health system being unable to cope with the increasing demand, forcing it to return dying patients to their families to free up hospital beds for other patients (Johnson, 2010).

Although not all families may necessarily respond to the challenges of HIV and AIDS in a similar way, the research shows, nonetheless, that many families do endure a lot of strain as a result of the impact of HIV and AIDS on the family and household structure as well as the socio-economic and emotional dimensions of family life.

#### **4.4 CULTURAL CONTEXTUALIZATION OF AFRICAN FAMILY LIFE**

African families are traditionally extended, with a dominant father as the head. Large changes in urban families have taken place primarily as a result of urbanization, housing problems, political factors (the migratory labour system), and economic underdevelopment coupled with poverty (Bozalek, 1999). However, nuclear families have formed within the high socioeconomic group. The high incidence of out of wedlock births has resulted in the replacement of the nuclear family with other structures. In many cases the daughter and child live with the mother, which means that many multigenerational families exist (Steyn, 1993). This could be perceived as a protective factor against family disintegration in the face of HIV/AIDS.

Economic development in areas of mining, harbours, and industrial growth resulted in the migrant labour system. This meant that the workers (men) moved to other areas alone to work and earn an income. A portion of the money was then sent to the family in the rural area. However, many people who live away from their place of origin often return to their homes and families when they can no longer earn a living or when they need extensive care (Knobel & Van Landingham, 2003). In the course of time, family members were allowed to live together near the workplace under certain conditions. However, traditional family structures could not continue in this industrial environment. Differences between families in urban and rural areas can be ascribed to the effects of industrialization, urbanization and the migrant labour system (Nzimande, 1996; Bozalek, 1999). Migrant labour system was an apartheid structure which separated families; inherent in this system

comes the entrenchment of patriarchal nature of African families where the father ends up having more than one family with the negative consequences of potential exposure to HIV/AIDS both for himself and the two partners through multiple partner risk elevation (HSRC, 1994). Although ethnically different, all African families seem to share some characteristics: the importance of children, a happy family life, strong family ties, the nature and implication of being married and the need for togetherness, especially in the face of adversity (Nzimande, 1996; Bozalek, 1999). This could be applicable even in the present era where families are faced with the trauma of caring for members with HIV/AIDS.

#### **4.5 CHANGING STRUCTURES AND FUNCTIONS OF FAMILIES AFFECTED BY HIV/AIDS**

Family structures have been changing in response to urbanization, political events, civil conflicts and economic crises (McNeil, 1998; Wines & LaFraniere, 2004). HIV/AIDS and resulting death of fathers, mothers, children and siblings due to changes the very structure of this primary building block and is exacerbated further by the additional financial constraints placed on the family (Collins & Leibbrandt, 2007).

The social relations of individuals living with and families affected by HIV/AIDS often undergo significant modification. While families continued to represent a substantial source of assistance for the ill, such support typically decreased overtime. The conviction that the family can resolve all problems is beginning to weaken. The establishment of support organizations for AIDS patients and their families may enable them to cope more effectively with the disease and its consequences (McNeil, 1998; Wines & LaFraniere, 2004).

Family members often find themselves faced with the responsibility of caring for the infected physically deteriorating member/s. In the African family, the centralization of resources and support as well as the coming together of family members including the extended families seem to boost the resilience

of the primary caregivers (Steyn, 1993). Family resources get depleted as a result. However, when the stress levels hit their highest intensity family dysfunction indicators start to set in.

#### **4. 6 CULTURAL PERCEPTION OF HIV/AIDS**

From an African perspective, which is extremely stereotyped, illness is perceived as caused by witchcraft and is something that could be healed or cleansed by traditional healers through the performance of traditional rituals. This should also include physical ailment related to HIV/AIDS. The beliefs around the fact that ailments are externally controlled and connected to mystical beliefs may appear outrageous, but then at the same time tend to enhance the coping mechanism of the sick individuals as well as for the family caregivers. Individuals who are sick and also those infected by HIV/AIDS are made to believe that their disease is only temporary and once the rituals are performed they will eventually become healed. This provides hope for the infected and the caregivers strengthening their resilience even more, thus making coping much easier (Triandis, 1994).

African culture is not quick to stigmatize ailing individuals, rather, the culture does have a protective mechanism which tends to focus on making those infected and affected feel better and worth living. This approach, when practised, allows the infected and affected persons to have low stress level which has the capacity to boost the immune system, and the individuals are likely to live longer. However, nowadays, stigmatization seems to be emerging as a problem in the culture, especially in relation to HIV/AIDS infections. This makes it difficult to have the disease treated as any other disease within the culture, thus making care giving more stressful (Triandis, 1994; Baylies, 2002).

#### **4.7 FAMILY AND HOUSEHOLD RESPONSES TO HIV/AIDS**

To mitigate the impact of a shock like HIV/AIDS, a number of strategies may be employed by families and households. For example, a household may diversify its livelihood strategies. That is, a household may mobilize and strengthen assets, increase production, reduce consumption, and call on social relationships in order to minimize risk and adversity (Ellis, 1998). Another common coping mechanism is that of fragmenting and reforming households (Young & Ansell, 2003). Janjaroen (1998) reports that in Thailand when an economically productive household member dies, household members may leave and join other households. Migration has traditionally been undertaken by men for economic reasons. Africans find it easy to identify with extended family members such as aunt, uncles and grandparents outside the nuclear family as confidante.

Currently, household “leavers” and “joiners” tend to be children in Lesotho and Malawi (Young & Ansell, 2003). Households use reduction in size through child migration as a coping and survival strategy. Children who out migrate usually find themselves in the care and support of the extended family, a traditional safety net. While acknowledging that children belong within families, their kin and other social networks may be less than welcoming to foster them. In instances where traditional safety nets are unable or unwilling to foster children, these may be vulnerable to abuse, have to head households, drop out of school, seek paid employment, care for younger siblings, and may be forced into early sexual relations or marriage in order to secure their own livelihood and that of their siblings (Young & Ansell, 2003).

Family dysfunction and how it can be addressed need to be explored. Cultural traditions influence family and household responses to HIV/AIDS (Belsey, 2005). Where polygamy is still practiced (i.e. a man can take more than one wife), a child may still have a mother after the death of his/her own biological mother and will have access to resources which are usually located within a compound. Remarriage by a father, after the death of a mother, may render children vulnerable as a new wife may not be willing to care for children from

a husband's "previous" marriage. Also, where widows are inherited by a husband's brother upon the death of a husband, household headship is assumed by the husband's brother. Traditionally this practice is done to ensure family continuity and protection of the deceased's family and belongings. This practice started in the early traditional years and is still practiced within those families that adhere to those traditional values. While widow inheritance may protect a widow and her children from loss of assets because of property grabbing, it can contribute to the spread of HIV when a husband has died from an AIDS related illness. Child upbringing and care are a primary maternal role. However, the role of men in child upbringing and family life is paramount and needs to be promoted if families and households are to fulfill their obligations to children. Further, protective cultural practices and traditions need to be identified and promoted (Belsey, 2005).

#### **4.8 CONCLUSION**

Chapter four focused on the African cultural contextualization of family stress and HIV/AIDS. Families are overly impacted by the increasing numbers of members who are sick and physically deteriorating because of HIV/AIDS. Consequently this leads families into being overburden by the cultural expectations of caring for their sick members. This chapter also explored the bond within the extended African family structure and cultural perceptions of HIV/AIDS and family, as well as the household responses to HIV/AIDS. The next chapter will focus on research methodology used for the current study.

## **CHAPTER 5**

### **METHODOLOGY**

#### **5.1 INTRODUCTION**

This chapter deals with the methodological aspects used in the study. The rationale for the method chosen is provided, as well as the process of selecting the participants for the study and the data collecting instruments used are discussed. Furthermore, the procedure followed and the statistical methods employed are elaborated.

#### **5.2 RESEARCH DESIGN**

A quasi experimental design was used in the study. This approach enabled the exploration and comparison of the impact of caregiving on affected families and how the experienced stress is moderated in those families using between groups experimental control methods. Family qualities were regarded as independent variables and family adaptability as dependent variable. Various models were designed to test the moderation effect of the family qualities on the stress levels of the affected families.

#### **5.3 SAMPLING**

Three-hundred and sixteen families were conveniently selected to participate in this study. One hundred and twenty-two came from the families who are affected by HIV/AIDS with regard to having HIV positive member who are sick and physically deteriorating. Control groups included hundred and thirty-two families who are affected by caring for family members suffering from non HIV/AIDS physical ailment such as diabetes mellitus, cancer, strokes etc. and the other sixty- two participants were from families not caring for or having any sick member. Family caregivers from both sets of families were used as primary participants, while the third group of non-affected families was used as the second control group. Family caregivers were anyone representing the

family and these included parents, grandparents, relatives and children irrespective of age or gender.

The inclusion criteria also covered immediate relatives of the surviving orphans in families where both parents had died. Participants were black South Africans from Ba-Pedi, Tsonga, Ndebele and Vha-Venda cultural groups. These are mainly ethnic groups who live in the area where the study was conducted viz. Limpopo Province.

Affected families were identified from the patient register through the assistance of home based care centres, clinics and social workers' consultation rooms. Random sampling was conducted by taking every other family on the list to participate in the study. Such sampling procedure ensured that every family had equal chance of being selected for purposes of generalizability.

#### **5.4 INSTRUMENTS**

Questionnaires used to collect the data consisted of biographical questions, family resilience and stress questionnaires. A biographical questionnaire was used to gather information regarding family composition, employment, income, age, gender and religion of the respondent family members. Furthermore, they were asked to rate their family's stress and resilience on a different point Likert scale, ranging from 1 (very little) to 5 (very much).

The following family resilience questionnaires were used: Family Hardiness Index (FHI), Social Support Index (SSI), Relative and Friend Support (RFS), F-COPES, Family Time and Routine Index (FTRI), Family Problem Solving Communication (FPSC) Family Attachment and Changeability Index (FACI).

The Family Hardiness Index (FHI), developed by McCubbin, Thompson and McCubbin (1996), measures the internal strengths and durability of the family unit. This scale consists of 20 items, with three subscales (commitment,

challenge and control), 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 each statement describes their current family situation. The internal reliability (Cronbach's alpha) of the FHI is .82, and the validity coefficients range from .20 to .23 with regard to criterion indices of family satisfaction, time and routines, and flexibility (McCubbin et al., 1996).

The Social Support Index (SSI), developed by McCubbin, Patterson and Glynn, (1996), evaluates the degree to which families are integrated into the community and view the community as a source of support in that the community can provide emotional support (such as recognition and affirmation), esteem support (affection), and network support (relationships with relatives) (McCubbin, McCubbin and Thompson, 1993). This scale consists of 17 statements that are rated on a five-point scale of agreement, ranging from "strongly disagree" to "strongly agree". The SSI has an internal reliability of .82 (Cronbach's alpha), a test-retest reliability of .83, and a validity coefficient (correlation with criterion of family wellbeing) of .40 (McCubbin et al., 1996).

The Relative and Friend Support Index (RFS), developed by McCubbin, Larsen and Olson, measures the degree to which families use the support of relatives and friends as a coping strategy to manage stressors and strains (McCubbin et al., 1996). This scale consists of eight items relating to sharing problems or seeking advice from neighbours or relatives, each requiring a response on a 5-point Likert rating scale ranging from "strongly disagree" to "strongly agree". This scale has an internal reliability of .82 (Cronbach's alpha) and a validity coefficient (correlation with the original F-COPES) of .99 (McCubbin et al., 1996).

The Family Crises Oriented Personal Evaluation Scales (F-COPES) identifies the problem-solving and behavioural strategies utilized by families in crisis situations (Olson et al., 1985). This measuring instrument focuses on two

levels of interaction, namely: (1) individual to family system - the way in which the family manages crises and problems internally amongst family members, and (2) family to social environment – the way in which the family manages problems outside its boundaries, but which still have an influence on the family as a unit. F-COPES consists of 30 5-point Likert-type items. High scores are an indication of effective positive coping behaviour.

The scale consists of five subscales that are again divided into two dimensions, namely: (1) internal coping strategies of the family, and (2) external coping strategies of the family. Internal coping strategies of the family define the way in which crises are managed by using support resources inside the nuclear family system. External strategies refer to the active behaviour that a family adopts to elicit support resources outside the nuclear family system (Olson, Portner, & Bell, 1989). The internal strategies are: (1) reformulating or redefining the problem in terms of the meaning it has for the family (positive, negative, or neutral) (Cronbach Alpha =.64), and (2) passive appreciation (Cronbach Alpha =.66); the family's tendency to do nothing about crisis situations. This avoidance response is based on a lack of confidence in own potential to change the outcome. The external strategies are: (1) use of social support, for example friends (Cronbach Alpha =.74), family members (Cronbach Alpha =.86) and neighbours (Cronbach Alpha =.79); (2) the search for religious support (Cronbach Alpha =.87); and (3) the mobilization of the family to get and accept help (for example professional help and the use of community resources) (Cronbach Alpha =.70).

A test-retest reliability coefficient of .71 was obtained after five weeks, and an internal reliability coefficient (Cronbach Alpha) of .77 was obtained for the total scale (Reis & Heppner, 1993). The construct reliability of the questionnaire was proven with a factor analysis and a varimax rotation of the axes. Five factors were isolated, with the factor loadings of the items being between .36 and .74. All five factors had Eigen-values larger than one (Olson et al., 1989).

The Family Time and Routine Index (FTRI) was developed by McCubbin, Thompson and McCubbin (1996) to assess the type of activities and routines families use and maintain and the value they place upon these practices. The FTRI is a 30 item scale consisting of the following eight subscales: Parent-child togetherness, couple togetherness, child routines, meal's together, family time together, family chores routines, relatives' connection routines, and family management routines. A respondent assesses the degree to which each statement (False, Mostly false, Mostly true, True) describes their family behaviour. The overall internal reliability is .88 (Cronbach's alpha) and validity was confirmed through significant correlations with various criterion indices of family strengths (McCubbin et al., 1996).

The Family Problem Solving Communication (FPSC) index was developed by McCubbin, Thompson and McCubbin (1996) to assess the two dominant communication patterns in families during hardships and catastrophes. The FPSC is a 10-item instrument with a four-point Likert scale (False, Mostly false, Mostly true, True). The two subscales are Incendiary, and Affirming communication. The alpha reliability of the subscales are .78 (Incendiary) and .86 (Affirming), and the alpha coefficient for the total scale is .89. The validity of the scale was confirmed in several large studies of families under stress, within various ethnic groups (McCubbin et al., 1996).

The Family Attachment and Changeability Index 8 (FACI 8) was adapted from the Family Adaptability and Cohesion Evaluation Scales (Olson, Portner, & Bell, 1989) by McCubbin, et al., (1996) as a measure of family functioning which would be ethnically sensitive. According to Fleming, Jory and Burton, (2002) FACI 8 consists of 16 items (6-point Likert scales) measuring the family's level of Attachment (cohesion) and Changeability (flexibility). Reliability (Cronbach's alpha) for the subscales varies between .75 and .80. Validity was established by determining the FACI8's relationship to a treatment programme's successful outcome (McCubbin et al., 1996).

Relative Stress Scale is a burden scale used to measure the stress levels of family members when involved with caring for an ailing member of the family. The scale was adapted from its original use of assessing the stress levels of individual caregivers so that it could be able to assess stress of caregivers within a family collective context in the present study. In this research, the families are involved in caring for members physically deteriorating due to HIV/ AIDS or any other chronic condition, while the third group of families is not involved in caring for a sick member at the time of the study. The scale consists of 15 items, scored at levels of intensity, from 0- not at all, to 4- to a higher degree, (Ulstein, Wyller & Engedal, 2007). It has a Chronbach of 0.91, and a factor analysis resulted in a three factor solution. It is as stated by the key family representative giving answers accordingly; how he has been observing his family through changes and how the illness has affected the family.

## **5.5 PROCEDURE**

Research was conducted in various areas of Limpopo Province which are Zebediela, Mankweng, Makhado and Polokwane. Permission and consent was sought from different community leaders and health and social development facilities, as well as from the identified families through the assistance of the home-based care agents. Research families were identified with the help of the home-base care agents who are mostly involved in the care of the sick in those families.

Appointments were secured with (each) of the identified families and those that consented to participate in the study in order to collect data. After the aim of the research project had been explained to the participants, they were asked if they still were willing to participate in the project. In cases where the family did not want to participate, another family was identified. During the visits, the confidentiality of the information and the anonymity of the participants were re-emphasized.

The aim, purpose and method of the investigation was then explained to the participants. They were invited to ask questions should anything be unclear to them. Each family was individually visited at the agreed time with the researcher. Questionnaires were handed out to the family representatives to respond on behalf of the family. Questionnaires were presented according to a specific order as set by the researcher. First, they were requested to complete the biographic information followed by resilience questionnaires and next the Family Attachment Changeability Index (FACI) and last was the Relative Stress Scale (RSS).

The family representatives, who in most cases were the most senior members of the families, were urged to give responses that represent the trends and practices observed in the family as people who are involved in the care of their family member. In child headed families, the eldest child in the family became the preferred person to complete the questionnaires.

The questionnaires were presented in the family's preferred language, completed in one visit and were administered by the chief researcher who is a clinical psychologist or a research assistant who was well-trained in collecting social research data. Time of resting was allowed during the session if the need was indicated.

## **5.6 DATA ANALYSIS**

Data were analyzed using Statistical Package for the Social Sciences (SPSS) (version 22.0). The data from the biographical questionnaire was represented as frequencies in table form. Analysis consisted of comparison of means, correlation and regression analyses. Correlation and regression analyses were calculated with the FACI (measure of adaptability) as dependent variable and all other measures (including the biographical data) as independent variables. The significant correlations were identified as resilience factors in line with the ABCX model that holds that variables that are significantly correlated with FACI (adaptability) make up the factors representing resilience. Stress levels among the research families were also

identified compared; and various models designed to test the moderation effect of family qualities on the stress experienced while caring for the sick family member.

## **5.7 ETHICAL CONSIDERATIONS**

### **5.7.1 Permission**

Permission to conduct this research was obtained from the following structures: Ethics committee of the University of Limpopo, Department of Health and Welfare and the eldest members of family or the selected family members who served as the spokes persons of the families. Consent to participate was sought before commencement with the process of data collection. Ethical issues in terms participation were outlined to all participants and observed by the researcher.

### **5.7.2 Confidentiality**

The confidentiality of the information and the anonymity of the participants were re-emphasized. The aim and method of the investigation was then explained to the participants. They were invited to ask questions should anything be unclear to them. Due to the sensitivity of the topic, caution was applied to avoid re-traumatization.

### **5.7.3 Anonymity**

Anonymity of the families and members interviewed was emphasised in the consent form. Members were not allowed to provide any information (such as names and surnames of the family, sick member etc.), that would jeopardise the anonymity of the family.

#### **5.7.4 Participants' after Care**

Participants who seemed to be emotionally affected by the research were referred to the local health care facilities for psychological support.

### **5.8 CONCLUSION**

This chapter outlined the methodology used in the study. The study used the quantitative approach to explore and compare stress and dysfunction in families caring for members physically deteriorating due to HIV/AIDS, families involved in caring for members ailing due to any chronic condition such as diabetes mellitus, cancer and stroke; besides HIV/AIDS and those not involved in caring for an ailing member. Data were analysed using SPSS version 22.0. Regression analyses and Pearson's correlation were calculated with the FACI 8 as a dependent variable to determine both resilience and the moderating factors.

## **CHAPTER 6**

### **FINDINGS**

#### **6.1 INTRODUCTION**

In this chapter, the findings of the study are outlined and interpreted. Demographic characteristics of the study participants and the sick family members will be analyzed. The results outline a detailed analysis of stress and dysfunction in families; comparing families caring for members deteriorating due to HIV/AIDS, with those families caring for members suffering from any chronic condition, and those not caring for any ailing family member. The families are also compared on the basis of the specific resilience factors which moderate the effects of stress in the three different families. Thus, identifying the resilience factors that irrespective of their adversity, what makes it possible for those families to be able to revert to their normal functioning, often even to higher functioning than before.

#### **6.2 DEMOGRAPHIC CHARACTERISTICS OF THE STUDY PARTICIPANTS AND THE SICK FAMILY MEMBERS**

The following section of the study focuses on the demographic characteristics of the study participants and the sick family members.

**Table 1: Demographic results of the research groups**

<b>Demographic variable</b>	<b>Frequency/ Percentage</b>		
	HIV/AIDS	Any Chronic Condition	Non HIV or Non Chronic
No of participants	122	132	62
<u>Gender</u>			
Male	55 (45)	46 (35)	0(31)
Female	67 (55)	86(65)	0(69)
<u>Age caregiver</u>			
<20	1 (1)	4 (22)	14 (22)
20-29	3 (3)	26 (23)	25 (39)
30-39	12(10)	22 (20)	17 (27)
40-49	23 (19)	27 (24)	1
50-59	21 (17)	15 (13)	0
60-69	23 (19)	8 (7)	0
70+	38 (31)	11 (9)	
<u>Ethnic group</u>			
Ba-Pedi	76 (81)	75 (57)	63 (100)
Vha-Venda	4 (4)	49 (37)	0 (0)
Other	14(15)	8 (6)	0 (0)
<u>Income</u>			
<20 000	111 (90)	93 (71)	23 (36)
20 001-40 000	8 (7)	19 (15)	8 (13)
41 000-60000	1 (1)	11 (9)	9(14)
>60 000	2 (2)	7 (5)	24 (38)
<u>Position of sick member</u>			
Adult & breadwinner	111 (83)	92 (0)	98 (0)
Young and dependent on family	2 (17)	19 (00)	2 (0)
<u>Age of sick member</u>			
<20	2 (8)	9 (0)	1(0)
20-29	3 (19)	21 (0)	2(0)
30-37	14 (17)	19(0)	11(0)
40-49	23 (23)	26(0)	19(0)
50-59	16 (13)	14(0)	13(0)
60-69	25 (8)	9(0)	20(0)
70+	40 (13)	14(0)	33(0)
<u>Gender of sick member</u>			
Male	54 (50)	59(54)	50 (46)
Female	54(50)	49(45)	50(46)

The study consisted of three hundred and sixteen families who completed the research questionnaires. One hundred and twenty two (n=122) families caring members physically deteriorating due to HIV/AIDS, one hundred and thirty-two families caring for members suffering from other chronic conditions besides HIV/AIDS (n=132) and sixty-two (n=62) families not involved in the caring for any sick members in the family.

Families involved in the caring for members physically deteriorating due to HIV/AIDS consisted of forty-five percent (45%) males and fifty-five (55%) females; families involved in the caring for members ailing due to any other chronic condition comprised thirty-five percent (35%) males and sixty-eight percent (68%) females and families not involved with caring of any member consisted of thirty-one percent (31%) males and sixty-nine percent (69%) females.

The age of participants in all families ranged between 20 and 70 years. The results indicate that caregivers within families caring for members physically deteriorating due to HIV/AIDS ranged between fifty (50) years and seventy 70+ and those involved in the caring of members physically ailing due to any other condition range from twenty (20) years to forty-nine (49) years. This indicates that family members actively involved in the caring for members in this study, within the families caring for members physically deteriorating due to HIV/AIDS were older, as compared to those caring for members ailing due to any other chronic condition. The sample of families not involved in caring for ailing family members consisted of younger participants than the other two research groups.

Among the families caring for HIV/AIDS physically deteriorating members 76 (81%) were Ba-Pedi, 4 (4%) Vha-Venda and other ethnic groups were 14 (15%). Those caring for family members suffering from other chronic conditions were 75 (57%) Ba-Pedi, 49 (37%) Vha-Venda and other ethnic groups were 8 (6%). The families where there was no ailing member to care for, were 63 (100%) Ba-Pedi.

Regarding the position of the ailing member, ninety-eight percent (98%) of members deteriorating due to HIV/AIDS were adults and breadwinners, while 83% of their ailing members due any other conditions were younger and depended on the older members for care. Ailing members in the HIV/AIDS affected families showed high prevalence of HIV amongst the oldest sick members (age 70+; n= 40). As compared to the younger group 30- 37(n= 2). This is a very interesting pattern of the prevalence of HIV/AIDS which might require more research in the future to account for such a discrepancy in age and HIV/AIDS infection. In families caring for member deteriorating due to HIV/AIDS research group were adults and breadwinners in the family, while eighty-three percent (83%) of the ailing members in families caring for members physically deteriorating due to any chronic condition were younger and dependent on older family members for care.

Ninety percent (90%) of families caring for members physically deteriorating due to HIV/AIDS earned between R20 000 and less per year, seventy-one percent (71%) of the families caring for members ailing due to any other chronic condition also earned between R20 000 and less per year. Thirty-eight percent (38) of families not caring for any family member earned between R60 000 and more. More families in this study came from the low income bracket.

### **6.3 STRESS AND RESILIENCE OUTCOMES**

#### **6.3.1 Experience of stress by families**

The relative stress scale was used to determine the levels of stress by the families in the study. The scores in table 2 indicate that the families caring for members that are physically deteriorating due HIV/AIDS experience more stress ( $X=18.3$ ) than the families caring for members that are suffering from any other chronic disease ( $X=14.6$ ). Families caring for members that are physically deteriorating due to HIV/AIDS were also found to be experiencing more stress as compared to families not involved in caring for an ailing family member ( $X=.03$ ). This also indicated that stress in both families caring for

members that are suffering from some chronic conditions as well as those families that are not directly involved in caring for an ailing family member experience less stress in comparison to families that care for members who are physically deteriorating due to HIV/AIDS.

**TABLE 2: Mean experience of stress by family type**

	Type of family	N	Mean	Std. Deviation
STRESS	1.Families caring for HIV/Aids ailing Members	122	18.3197	13.42704
	2.Families caring for chronically ill members that are non-HIV/AIDS sufferers	132	14.6667	8.90721
	3. Families not involved in caring for an ailing member	62	.0323	.17813
	Total	316	13.2057	12.14223

Table 3 below shows comparison of the three families with respect to the experience of stress. The results indicated that stress differs significantly among the three families ( $F= 69.149$ ;  $df=2$ ,  $p<0.05$ ). The post hoc test indicated that higher stress is in families caring for members physically deteriorating due to HIV/AIDS, followed by families caring for members physically deteriorating due to any chronic conditions, and lastly by those families who are not caring for any sick person. The results indicate that stress is higher in families caring for members physically deteriorating due to HIV/AIDS as compared to other two types of families.

**TABLE 3: ANOVA between family typology and stress**

RSS	Sum of Squares	Df	Mean Square	F	Sig
Between Groups	14231.828	2	7115.914	69.149	0.000*
Within Groups	32209.802	313	102.907		
Total	46441.630	315			

\*Significant at p<0.05

### 6.3.2 Experience of stress by demographics

The following part of research focuses on the demographic characteristics among the three research groups of families. Table 4 shows the relationship between stress levels and the demographics such as gender, position held by sick member in the family and the socio-economic level of the family as well as the stress levels.

**TABLE 4: Demographic characteristics of the study participants**

	Families caring for member physically deteriorating due to HIV/AIDS		Families caring for member physically deteriorating due to any chronic condition		Families not involved in the caring of an ailing member		p-value
	No	%	No	%	No	%	
<b>Gender</b>							
male	1	54	45	35	32	20	31
Female	2	67	55	76	68	44	69
<b>Age</b>							
<20	1	1	4	4	14	22	
20-29	3	3	26	23	25	39	
30-39	12	10	22	20	17	27	
40-49	23	19	27	24	7	10	0.001*
50-59	21	17	15	13	1	1	
60-69	23	19	8	7	0	0	
70+	38	31	11	9	0	0	
<b>Language</b>							
Sepedi	76	81	75	57	63	100	
Tshivenda	4	4	49	37	-	-	0.001*
Other	14	15	8	6	-	-	
<b>Income</b>							
≤R20 000	111	90	93	71	23	36	
R20 001-R40 000	8	7	19	15	8	13	
R41 000-R60 000	1	1	11	9	9	14	0.001*
>R60 000	2	2	7	5	24	38	

\*significant at P<0,05

### **6.3.2.1      Age status**

There were significant statistical differences between the three groups with regard to age of care givers and stress level in the family ( $p<0.001$ ). There was indication of higher stress level within the age groups of (50–70) years and above, for families with HIV/AIDS deteriorating members and for the age group within the (20-49) range for the families caring for member chronically ill due to any chronic condition, and the age group within the (14-27) years of age for the families with no ailing family member. This indicates that stress levels are found to be higher when the care givers are older and in families caring for HIV/AIDS members as compared to the care givers in the control groups.

### **6.3.2.2    Experience of stress by language groups**

A significant stress impact for these families was found in the three groups for the Ba-Pedis and the impact on the families of members with other chronic ailments was significant for the Vha-Vendas.

### **6.3.2.3    Experience of stress by Income**

The significant impact of stress was found to be among high earners for both family groups with ailing members as compared to those with families not affected by ailing members. There were statistical significant differences between the three groups with regard to income ( $p<0.001$ ). This indicates that low earners as against high earners were affected by stress for both families caring for the HIV/AIDS suffering members and the those caring for chronically ill family members that are not HIV/Aids sufferers. This differed from those who do not have an ailing family member.

### 6.3.2.4 Gender status

According to the results no significance difference was noted between the three groups with respect to the impact of stress and gender ( $p<.069$ ). This means family members of both genders experience stress equally in the care of the ailing members.

### 6.3.2.5 Demographic information of the sick person within the family

Table 5 represents the demographic information about the sick person within the family such as gender, age, and position of a sick member within the family and the frequency of experience of stress.

**TABLE 5: Comparison of the frequency of experience of stress levels by demographics between families caring for non HIV/AIDS chronically ill member and HIV/AIDS sufferer**

	Families caring for member physically deteriorating due to HIV/AIDS		Families caring for member physically deteriorating due to any chronic condition		p-value
	No	%	No	%	
<b>Gender of sick member</b>					
M	54	50	59	55	0.496
F	54	50	49	45	
<b>Age of sick member</b>					
<20	2	1	9	8	0.001*
20-29	3	2	21	19	
30-39	14	11	19	17	
40-49	23	19	26	23	
50-59	16	13	14	13	
60-69	25	20	9	8	
70+	40	33	14	13	
<b>Position of the sick member in the family</b>					
Adult & breadwinner	111	98	92	83	0.001*
Young and dependent on family members	2	2	19	17	

\*Significant at  $p<0.05$

### **6.3.2.6 Level of stress and the gender of a sick member in the family**

The study indicates that there was no significant difference in the experience of stress on members caring for either males and females in families caring for members physically deteriorating due to HIV/AIDS and families caring for members deteriorating due to any chronic condition other than HIV/AIDS ( $p<0.496$ ). This means that for both groups of families caring for either male or female patient did not show any differences in stress levels for the caregivers (See Table 5).

### **6.3.2.7 Level of stress and the age of a sick member in family**

Significant differences were noted on stress impact for the family with an HIV/AIDS sufferer and families caring for non HIV/AIDS chronically ill members and the age of the ill member. Both groups are affected by caring for young adults in the year range of (20-39) and the elderly in the age range of (60-70+). More members ( $n=65$ ) in the HIV affected families as compared to the families caring for members with non-HIV/AIDS chronic illness are affected by caring for young adults ( $p< .001$ ); and these families with non-HIV/AIDS chronically ill members ( $n=40$ ) seem to be affected by stress when caring for a younger person as compared to  $n=17$  for HIV/AIDS affected families ( $p< .001$ ).

There was no difference in stress levels noted among the two family groups, those caring for members physically deteriorating due to HIV/AIDS chronically ill) when caring for members at mid adulthood (See Table 5) .

### **6.3.2.8 Position of a sick member in the family**

The study further indicates that there is a significant difference in the experience of stress levels between members in both research groups with regards to the position held by the sick member in the family. More members from the HIV/AIDS caregivers group ( $n=111$ ) experience higher stress level

than those from the families caring for the chronically ill (n=98) ( $p<0.001$ ). Stress is higher if the sick member is an adult and a breadwinner than if the sick member is younger and has less responsibility in the family (SeeTable 5).

## **6.4 POTENTIAL RESILIENCE FACTORS BY FAMILY TYPE**

Potential resilient factors were found by variables which significantly correlated with the family measurement of adaptability through the use of the scale FACI (Family Attachment and Changeability Index) as per the model for this study. The findings indicate that there are potential resilience factors which differ according to families. The factors are discussed below.

### **6.4.1 Potential resilience factors among families caring for family members physically deteriorating due to HIV/AIDS**

The potential resilient factors among families caring for family members physically deteriorating due to HIV/AIDS identified as per model for this study was Family Time and Routine Index (FTRI).

#### **6.4.1.1 Family time and routine index (FTRI) factor**

Family time and routine index (FTRI), a factor highlighting the importance of a family's ability to spend time together was the only resilience factor that showed significant correlation with FACI in terms of families caring for members physically deteriorating due to HIV/AIDS. Table 6 represents correlation between the FACI and FTRI, as well as the FTRI significant sub-items.

**TABLE 6: Pearson's correlation between FACI and FTRI.**

FTRI Items	FACI	
	R	P-value
11a. Parents have a certain hobby or sport they do together regularly.	-.200	.025*
12a. Parents have time with each other quite often.	.279	.002**
15(a). Children have special things they do or ask for each night at bedtime (e.g. story, goodnight kiss, hug, etc.)	.339	.001**
3a. Working parent takes care of the children sometime almost every day.	.191	.000*
3b. How important to keeping the family together and united.	.199	.000*

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

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

Families caring for family members physically deteriorating due to HIV/AIDS use FTRI as a potential resilient factor ( $r=.220$ , and  $p<0.05$ ). The FTRI items that were significantly correlated with FACI included items 3(a) and 3(b), 11(a), 12 (a) and 15 (a) (See Table 6). Item 3(a): "working parents take care of children some time and almost every day" ( $r=.191$  and  $p<0.01$ ). Item 11(a): "parents have a certain hobby or sport they do together regularly" ( $r=-0.200$  and  $p<.05$ ). Item 12 (a): indicates that "parents have time for each other quite often" ( $r=.279$  and  $p< 0.01$ ). Furthermore, Item 15(a): "children have special things they do or ask for each night at bedtime" (e.g.) good night kiss, hug, etc. ( $r=.339$  and  $p<0.01$ ).

#### **6.4.2 Potential Resilient factors among families caring for family members physically deteriorating due to any other chronic illness**

The potential resilient factors among families caring for family members physically deteriorating due to any other chronic illness were identified by highlighting factors that correlated significantly with FACI as described above. For these family groups, the potential resilience factors identified were Social

Support Index (SSI), Family Time and Routine Index (FTRI) and Family hardiness Index (FHI).

Table 7 represents correlation between the FACI with SSI, FTRI and FHI, as well as the significant sub items of these resilience factors.

**TABLE 7: Pearson's correlation for FACI with other resilient factors in families caring for members suffering from any other chronic illness.**

	FACI	
Resilient factors	R value	P
FHI	.313	.018*
FTRI	.411	.002**
SSI	.296	.027*

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

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

#### **6.4.2.1. Social Support Index (SSI) factor**

SSI is a significant resilient factor for families caring for ailing members suffering from chronic conditions other than HIV/AIDS ( $r=.296$ ,  $p<0.01$ ). This indicates that social support contributes to resilience in families caring for members suffering from any chronic condition as compared to families caring for members deteriorating due to HIV/AIDS. Table 7 shows the specific items indicating significant correlations between FACI and SSI in families caring for members physically ill due to any chronic illness. The sub items are 2,7,10,11,14,17.

Item 2:"members feel good about themselves when they give time and energy to members of the family" ( $r=-.280$ ,  $p<0.05$ ); item 7: "members of my family often do not listen to my problems and concerns, I usually feel criticized" ( $r=.450$ ,  $p<0.01$ ). Item 8: "My friends in the community are part of my everyday activities" ( $r=.300$ ,  $p<0.05$ ). Item 10: "I need to be careful how much

I do for my friends because they take advantage of me" ( $r=.385$ ,  $p<0.01$ ). Item 11:"living in this community gives me secure feelings" ( $r=.314$ ,  $p<0.01$ ). Item 14:"this is not a very good community to bring children up in" ( $r=.645$ ,  $p<0.01$ ).

Stronger correlations are noted with expression of negative feelings which indicate level of awareness of ones position in the society and how one can thus be able to adapt. This could be in line with feelings of being drained by the sick family member and still not having feelings of being stigmatized.

**TABLE 8: Pearson's correlations for FACI and SSI in families caring for Members suffering due to any chronically ill family members.**

FACI		
Social Support Index (SSI)	r value	P value
2. I feel good about myself when I sacrifice and give time and energy to members of my family	.280	.032*
7. Members of my family seldom listen to my problems or concerns; I usually feel criticized	.450	.000**
8. My friends in the community are part of my everyday activities	.300	.021*
10.I need to be very careful how much I do for my friends because they take advantage of me	.385	.003**
11. Living in this community gives me secure feelings	.314	.016*
14. This is not very good community to bring children up in	.642	.000**
17. Member(s) of my family do not seem to understand me; I feel taken for granted	.257	.049*

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

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

#### 6.4.2.2 Family Hardiness Index (FHI) factor

FHI was found to be the potential resilience factor in families caring for members suffering from any other chronic condition ( $r=.313$  and  $p<0.05$ ) (See Table 7). This indicates that family hardiness is one of the factors which contribute to resilience in families caring for members suffering from any chronic condition as compared to families caring for members deteriorating due to HIV/AIDS.

Specific items indicating correlations between FACI and FHI in families caring for members physically ill due to any chronic illness are shown in (Table 9) and include items 2, 3, 4, 6, 7, 8. Item 2 : "it is not wise to plan ahead and hope because things do not turn out any way" ( $r=.554$  and  $p<.01$ ); Item 3:"our work and efforts are not appreciated no matter how hard we try and work" ( $r=.513$ ,  $p<0.01$ ); Item 4 : " We do not feel we can survive if another problem hits us" ( $r=.323$ , $p<0.05$ ); Item 6 : " Life seems dull and meaningless" ( $r=.513$ ,  $p<0.01$ ) Item 7: We tend to do the same things over and over its boring ( $r=.375$ ,  $p<0.01$ ); Item 8: "we do not feel we can survive if another problem can hit us" ( $r=.585$ ,  $p<0.01$ ).

**TABLE 9: Pearson's correlations for FACI and FHI in families caring for members suffering due to any chronically ill family members.**

FACI		
	r value	P value
Family Hardiness Index		
2. It is not wise to plan ahead and hope because things do not turn out anyway	.554	.000**
3. Our work efforts are not appreciated no matter how hard we try and work	.513	.000**
4. We do not feel we can survive if another problem hits us	.323	.013*
6. Life seems dull and meaningless	.513	.000**
7. We tend to do the same things over and over it's boring	.375	.003**
8. It is better to stay at home than go out and do things with others	.585	.000**

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

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

#### **6.4.2.3 Family time and routine index (FTRI) factor**

FTRI as well, is a potential resilience factor in families caring for members physically deteriorating due to any other chronic disorder ( $r=.411$   $p<0.01$ ) (See Table 7). This indicates that family time and routine plays an important role as a factor which contributes to resilience in families caring for members suffering from any other chronic condition.

The specific items indicating correlations between FACI and FTRI in families caring for members physically ill due to any chronic illness are item 4, 5, 7 and 8. Item 4: "Non-working parent and children do something together outside the home almost every day" ( $r=.223$ ,  $p<0.05$ ); Item 5: "Family has a quiet time each evening when everyone talks or plays quietly" ( $r=.315$ ,  $p<0.05$ ); Item 7 : "Family has a certain family time each week when they do things together at home" ( $r=.365$ ,  $p<0.05$ ); Item 8 : "Parents read or tell stories to the children almost every day" ( $r=0.13$ ,  $p<0.01$ ).

**TABLE 10: Pearson's correlations for FACI and FTRI in families caring for members suffering due to any chronic condition.**

FACI		
	r value	p value
Family time and routine index (FTRI)		
4. Non-working parent and children do something together outside the home almost every day (e.g., shopping, walking, etc.)	.223	.021*
5. Family has a quiet time each evening when everyone talks or plays quietly	.315	.013*
7. Family has a certain family time each week when they do things together at home	.365	.023*
8. Parents read or tell stories to the children almost every day"	.013	.022**

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

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

#### **6.4.3 Potential Resilient factors among families not involved in caring for an ailing family members.**

There was no correlation between FACI and potential resilient factors among families not involved in caring for an ailing family member.

#### **6. 5 FINDINGS ON THE MODERATION EFFECT OF FAMILY RESILIENCE FACTORS ON STRESS**

Both the univariate and multivariate analysis of data was used to determine the moderation effect of resilience factors on stress of families caring for members deteriorating due to HIV/AIDS and as compared to the two control samples of families caring for members physically deteriorating due to any other chronic condition and those families not involved in caring for an ailing member.

## 6.5.1 Stress Moderation effects highlighted for families caring for members physically deteriorating due to HIV/AIDS

### 6.5.1.1 Univariate regression analysis

The following part highlights the univariate regression analysis results of the moderation effect of resilience factors on stress among families caring for members deteriorating due to HIV/AIDS as compared to the two control samples of families caring for members physically deteriorating due to any other chronic condition, and those families not involved in caring for an ailing member.

**TABLE 11: The results of the univariate regression analyses (outcome=stress)**

	Families caring for member physically deteriorating due HIV/AIDS			Families caring for member physically deteriorating due to any chronic conditions			Families not involved in caring for an ailing member		
	B	SE	p-value	B	SE	p-value	B	SE	p-value
SSI	-0.28	0.17	0.10	-0.09	0.13	0.46	0.004	0.02	0.12
RFS	-0.41	0.27	0.13	0.02	0.18	0.89	-0.004	0.03	0.89
FPSC	0.91	0.26	0.01	-0.23	0.22	0.29	-0.004	0.05	0.35
FHI	0.34	0.12	0.01	-0.03	0.10	0.74	0.002	0.01	0.46
FCOPES	0.21	0.06	0.02	0.02	0.04	0.68	0.001	0.02	0.49
FAC18	0.15	0.02	0.47	-0.24	0.10	0.02	0.005	0.01	0.83
FTRI	-0.17	0.06	0.01	-0.18	0.06	0.01	-0.001	0.06	0.87

Univariate regression significant at 10-20 level

The factors that were found to moderate stress within the families caring for a

member physically deteriorating due to HIV/AIDS were SSI, RFS, FTRI, and non-stress moderating factors include FPSC FHI and FCOPES. This indicates that stress in these families is moderated by social support, relatives' and friends' support, family time and routine. Escalation of stress is due to the factors around engagement in family problem solving and communication as well as family crises oriented personal evaluation and family hardiness.

#### **6.5.1.1.1 Moderating factors for stress as highlighted by the univariate regression analysis**

##### **a. Social Support Index (SSI)**

The univariate regression analysis results (see table 11) indicate that SSI is a moderating factor for stress. As indicated in the table 11 above, a negative relationship exists between the SSI and stress/dysfunction in families caring for members physically deteriorating due to HIV/AIDS ( $B=-0.28, p<0.10$ ). This indicates that as social support increases the stress levels of families caring for members deteriorating due to HIV/AIDS decreases.

##### **b. Relative and Friend Support (RFS)**

Relatives' and friends' support (RFS) was found to have a significant negative effect with stress. This indicates that as the relative and family support increases, the stress within the families caring for members deteriorating due to HIV/AIDS decreases ( $B=-0.41, p< 0.1$ ).

##### **c. Family Time and Routine Index (FTRI)**

The other significant factor indicated as a moderating factor for stress was FTRI. The results ( $B=-0.17, p< 0.01$ ) indicate that as the family time and routine increases, the stress within the families caring for members deteriorating due to HIV/AIDS decreases.

**d. Family Problem Solving and Communication (FPSC)**

Positive relationship was observed for the FPSC factor and stress in families caring for members physically deteriorating due to HIV/AIDS ( $B=0.91$ ,  $p<0.01$ ). This indicates that as the family problem solving and communication tendencies increase, stress also increases in families caring for members physically deteriorating due to HIV/AIDS.

**e. Family Crisis Oriented Problem Solving Evaluation Scale (FCOPES)**

Positive relationship was observed with FCOPES ( $B=0.21$ ,  $p< 0.02$ ) factors. These indicate that as family crisis oriented problem solving evaluation abilities increase; stress within the families caring for members physically deteriorating due to HIV/AIDS also increases.

**f. Family Hardiness Index (FHI)**

Positive relationship was observed with Family Hardiness Index (FHI) factors ( $B=0.34$ ,  $p< 0.01$ ). These indicate that as family hardiness increases, stress within the families caring for members physically deteriorating due to HIV/AIDS also increases.

In summary factors responsible for stress moderation in HIV/AIDS affected families are SSI, RFS, and FTRI. The factors that escalate stress within the HIV/affected families are FPSC, FHI and FCOPES.

**6.5.1.2 Multivariate regression analysis**

The following part highlights the multivariate regression analysis results of the moderation effect of resilience factors on stress among families caring for members deteriorating due to HIV/AIDS as compared to the two control samples of families caring for members physically deteriorating due to any other chronic condition as well as those families not involved in caring for an

ailing member.

**TABLE 12: The results of the multivariate regression analysis  
(Outcome=stress)**

Families caring for member physically deteriorating due HIV/AIDS			Families caring for member physically deteriorating due to any chronic conditions			Families not involved in caring for an ailing member			
	B	SE	p-value	B	SE	p-value	B	SE	p-value
RFS	-0.72	0.26	0.01	-	-	-	-	-	-
FCOPES	0.27	0.06	0.01	-	-	-	-	-	-
FTRI	-	-	-	-0.18	0.06	0.01	-	-	-

Multivariate regression significant at 15-20 level

The multivariate regression analysis was used to determine the overall moderation effect of multiple resilience factors on stress of families caring for members deteriorating due to HIV/AIDS and the two control samples. The result indicated that the significant effect of multiple factors on stress for the family with HIV/AIDS sufferer were Relative and Friend Support (RFS) and Family problem solving and communication (FCOPES).

#### **6.5.1.2.1 Emerging moderating factors by multiple effects.**

##### **a. Relative and Friend Support (RFS) factor and stress.**

The multivariate regression analysis results indicate a high negative relationship between the Relative and Friend Support (RFS) and stress in families affected by HIV/AIDS ( $B=-0.72$ ,  $p<0.01$ ). This indicates that an increase in support to the families affected by HIV/AIDS by friends and relatives, the stress levels within those families decrease.

**b. Family Crisis Oriented Personal Evaluation Scale factor and stress**

The multivariate results also indicated a positive relationship between Family Crisis Oriented Personal Evaluation (FCOPES) and stress within families caring for members physically deteriorating due to HIV/AIDS ( $B=0.27$ ,  $p<0.01$ ). This therefore, suggests that as the Family Crisis Oriented Personal Evaluation (FCOPES) measures increase, stress within HIV/AIDS affected families also increases.

**TABLE 13: Multivariate regression analysis summary**

	Y	p-value
RSS	1.27	0.01
FTRI	1.10	0.01
RSS*FTRI	0.99	0.02

Significant at  $<.005$

Table 13 above summarizes the association between relative stress level (RSS) and FTRI and their interaction with HIV/AIDS affected families in comparison with non HIV/AIDS affected families caring for members suffering from due to any other chronic illness. RSS and FTRI were found to be more frequently common in HIV/AIDS affected families than in families affected by any other chronic illness. This implies that the HIV/AIDS affected families have high stress which is moderated by Family Time and Routine Index (FTRI).

**6.5.2 Stress moderation effects highlighted for families caring for member ailing from any other chronic condition other than HIV/AIDS**

Both the univariate and multivariate regression analysis in tables 11 and 12 indicate Family Time and Routine Index (FTRI) as the only significant resilient factor that moderate stress in non HIV/AIDS affected families. The results ( $B=-0.18$ ,  $p< 0.01$ ) indicate that as the family time and routine increases, the

stress within the non-HIV/AIDS affected families caring for members suffering from any chronic condition decreases.

A negative relationship between stress and FTRI indicates that as family time and routine increases, the stress within families caring for members suffering from any chronic conditions decreases.

## **6.6 THE CONCLUSION OF THE UNIQUE FINDINGS OF THE RESILIENCE FACTORS AND STRESS MODERATION FACTORS**

In terms of the results, Family Time and Routine Factor (FTRI) seem to be the common resilient factor that is readily available in both families to assist them to cope with adversity. This means that both family groups use connectedness and togetherness as a way of dealing with challenges of caring for their ailing family members. FPSC, FCOPES and FHI were found to escalate stress in the families. This implies that these families may have less preference to communicate in the family with possible avoidance of stigmatisation surrounding the condition of the sick member. It was however, noted that social support and the use of support by family and friends (aspects that are contrary to fear of stigmatisation) moderated the stress level in HIV/AIDS affected families. This shows that even though the families may not willingly want to engage external support, the support has an inherent impact on the experience of stress.

The next chapter will discuss the results reported in Chapter 6 in relation to theory and previous researches. Following the discussion, conclusions will be drawn so as to inform recommendations for future studies and the development of intervention programmes.

## **CHAPTER 7**

### **DISCUSSION**

#### **7.1 INTRODUCTION**

The aim of the study was to assess stress and dysfunction among families affected by the sudden reality of caring for the physically deteriorating members due to HIV/AIDS progression, and to identify resilience factors that moderate the impact of such stress in those families. The main objectives of the study were to explore the extent to which such families experience stress and dysfunction, and assess how stress levels in such families respond to available resilience factors.

The study focused also on determining if there was uniqueness in resilience factors that operate among families affected by HIV/AIDS compared to those that are affected by caring for a member ailing due to any other chronic illness, or those not caring for an ailing member, as well as to determine if there is any relationship between resilience strategies families use and the demographic background of family caregivers;, viz. gender, age and the role or position held by the ailing family member. This chapter will focus on the discussion of the results in relation to the above aims and objectives as well as describing the results within theoretical model used in this study of the existing McCubbin Resiliency model of stress, adjustment and adaptation.

In the discussion, resilience factors will be described using less technical abbreviations for purposes of making the reading of the discussion of the findings to flow smoothly. The following descriptions will apply for the highlighted resilience factors: FTRI factor will be referred to as indicator of “family togetherness or connectedness”, SSI and RFS as social support, FCOPES and FPSC as internal “family communication” and FHI as “family hardiness”. Furthermore, families caring for a member physically deteriorating due HIV/AIDS will be addressed as HIV/AIDS affected families; families caring for members suffering from any other chronic illness will be known as families affected by any other chronic condition, and families not involved in

caring for any ailing member will be addressed as non-affected families.

## **7.2 THE DEMOGRAPHIC FACTORS OF THE CAREGIVERS AND SICK PERSON WITHIN FAMILIES IN THIS STUDY**

The study looked at the demographic factors and characteristics of the caregivers and the sick person within the three families which contribute to resilience. The following discussion will explore the specific demographic outcomes of the study.

### **7.2.1 Age of caregivers**

The study noted differences in terms of age of caregivers in both affected families. Family members responsible for caring for the ailing within HIV/AIDS affected families were older as compared to the younger caregivers in families affected by any other chronic illness and non-affected families. This indicates that caregivers in HIV/AIDS affected families are often older than it was the case for both control groups. This is in line with the findings that HIV infections is increasing in the 20-35 age group Shisana and Simbayi (2014), which means that the older members of many affected families have to carry the burden of caring for their younger members. Icea et al., (2012) also concluded, based on similar findings, that age difference of caregivers in these families could be attributed to the fact that probably parents and grandparents are mostly the affected members in the family and available to take care of their HIV infected and ailing children and grandchildren.

Furthermore, the seriousness of the last stage of the physical progression of HIV/AIDS could also encourage the need by older members to protect the younger caregivers to take over the caring role for their HIV/AIDS ailing members as opposed to families caring for members ailing because of any other chronic condition which may not be as glaringly progressively life threatening as people suffering from AIDS. The difference could be that caring for family members ailing due to any chronic illness is not always tedious, as

often in such families members are able to help each other and the family is able to cope. In the African culture the intensity of the condition of the sick member often dictates that the most capable senior member of the family be entrusted with the responsibility of caring (Icea et al., 2012; Makoae, 2009).

### **7.2.2 Gender differences in caregiving**

Regarding gender of caregivers in the three families, female caregivers from poor family background were in the majority in both HIV/AIDS affected families and the control groups as compared to males within these families. This could be understood from the point that naturally, and according to the African cultural practices and tradition, women are often carers and nurturers, and are also expected to play a pivotal role whenever caregiving responsibility befalls a family. Therefore, it makes sense that women are highly involved in caring for their sick members irrespective of the type of illness the family member is challenged with. This concurs with study conducted by Boss (2002), stating that women's role obligate them to respond to the needs of others, and their caring role is more intense and persistent, thus making them more vulnerable to stress than men.

### **7.2.3 Sick Member position in the family**

The demographic differences within the three different families with regard to who the sick person is in the family, was also highlighted. The demographic information of the sick person within the family included gender, age, and position of the sick member within the three families.

### **7.2.4 Gender of the sick family member**

Gender was not identified as a predictive and significant variable in terms of the sick family member in this study. Nevertheless, it important to indicate that the above result implies that both families are equally affected irrespective of the gender of the sick family member. This could, therefore, imply that the

gender of the sick member does not directly influence caregiving or resilience within the researched families.

#### **7.2.5 Age of the sick family member**

A significant difference regarding the age of sick persons between the HIV/AIDS affected families and families affected by any other chronic condition was observed. The ages of HIV/AIDS sick members were found to range between 30 years and above, whereas the chronically ill members were mostly between 29 years and below. The reason for the difference could be associated with possibilities that younger family members often do not disclose their HIV/AIDS status probably due to fear of rejection and stigma. This gives an impression that adult people suffering from HIV/AIDS related conditions are in the majority as compared to those suffering from any other chronic illness.

The position held by the sick person in the family also appeared to yield a significant difference. Stress was found to be higher if the sick member is an adult and being a breadwinner than if the sick member is younger and dependent on older family members. This therefore, implies that the majority of family members caring for members physically deteriorating due to HIV/AIDS were found to be among adults caring for their children and other adult family members. In families caring for chronically ill members, sufferers are mostly younger and have less responsibilities and less stress. In other words, in the experimental families, sufferers were often adults and had to depend on adult and younger family members for care and support.

### **7.3 EXPERIENCE OF STRESS BY DIFFERENT FAMILIES**

The results concluded that the two caregiver family groups researched in this study differ in terms of the type of resilience factors available and the stress experienced when challenged with the adversity of caring for ailing members. The families are impacted differently according to the family typologies within

the present study, and the type of stress families experience, as well as their vulnerability state. HIV/AIDS affected families were found to be experiencing more stress as compared to families affected by any other chronic illness and the non-affected families.

The above findings could be associated with intense progression of HIV/AIDS condition and the impact it has on its victims, consequently the family. According to the progression of HIV/AIDS takes the form of four stages, the last being the progression from HIV related disease and AIDS. At this last stage the infected person develops HIV related opportunistic diseases and full blown AIDS to a point where they totally depend on members of their families for total care and support. Notably it is at this stage where most families are burdened with stress of fulltime care for their ailing members. However, according to Singh, Chaudoir, Escobar and Kalichman (2011), caregivers with more support systems experience low caregiver burden and are more likely to want to care for their HIV/AIDS affected member.

The mounting stress levels in HIV/AIDS affected families could also be associated with the stress caused by the shock of discovering a reality that one of the family members is actually diagnosed with HIV/AIDS, the stigma attached to HIV/AIDS, and the actual physical progression of the family member physically deteriorating due HIV/AIDS. This possibly pushes the stress in these families so high that it could not be compared with that of families caring for members suffering from any other chronic illness or those not involved in caring for any ailing member at the time.

HIV/AIDS affected families have more pile-up of stress and appear to be more vulnerable to stress than those families affected by any other chronic illness as well as those not involved in the caring of a sick family member. The impact that the stressor has on the family is partially determined by the severity of the stressor, such as caring for a member who is at the last stage of HIV/AIDS as compared to families caring for a member ailing due to a chronic condition. This as compared to other families has the potential to

cause severe stress, which is often determined by how much the stressor jeopardizes functioning, resources, and the stability of the family.

Families not involved in the caring for ailing members also experience less stress as compared to the HIV/AIDS affected families. In other words, caring determines and influences stress level, and caring for member infected by HIV/AIDS or any other chronic diseases seems stressful. In this case the implication is that caring increases the family's vulnerability, resulting in possible disintegration and fostering either maladaptation or bonadaptation in the family. The impact that the stress of caring has on the family is partially determined by the severity of the stressor; and the severity is determined by how much the stressor jeopardizes functioning, resources and stability of the family (McCubbin, 1990; McCubbin & McCubbin, 2001). The high stress level among HIV/AIDS affected families is explainable by the severity of the stressor of watching a family member glaringly progressing towards complete helplessness.

Findings also indicated elevated stress levels for the caregivers of younger family members and also for the members who were breadwinners as well as when the family had inadequate economic resources. These findings clearly indicate the multiple impact of caregiving and the sympathy felt for the young person who is seen as being wasted and still had many years ahead; and the impact of the socio-economic burden, which is in line with Eberhsonn's designed model of 3 r's (RRR) indicating that resilience has great connection to resources (Eberhsonn, 2012).

#### **7.4 POTENTIAL RESILIENCE FACTORS AMONG HIV/AIDS AFFECTED FAMILIES**

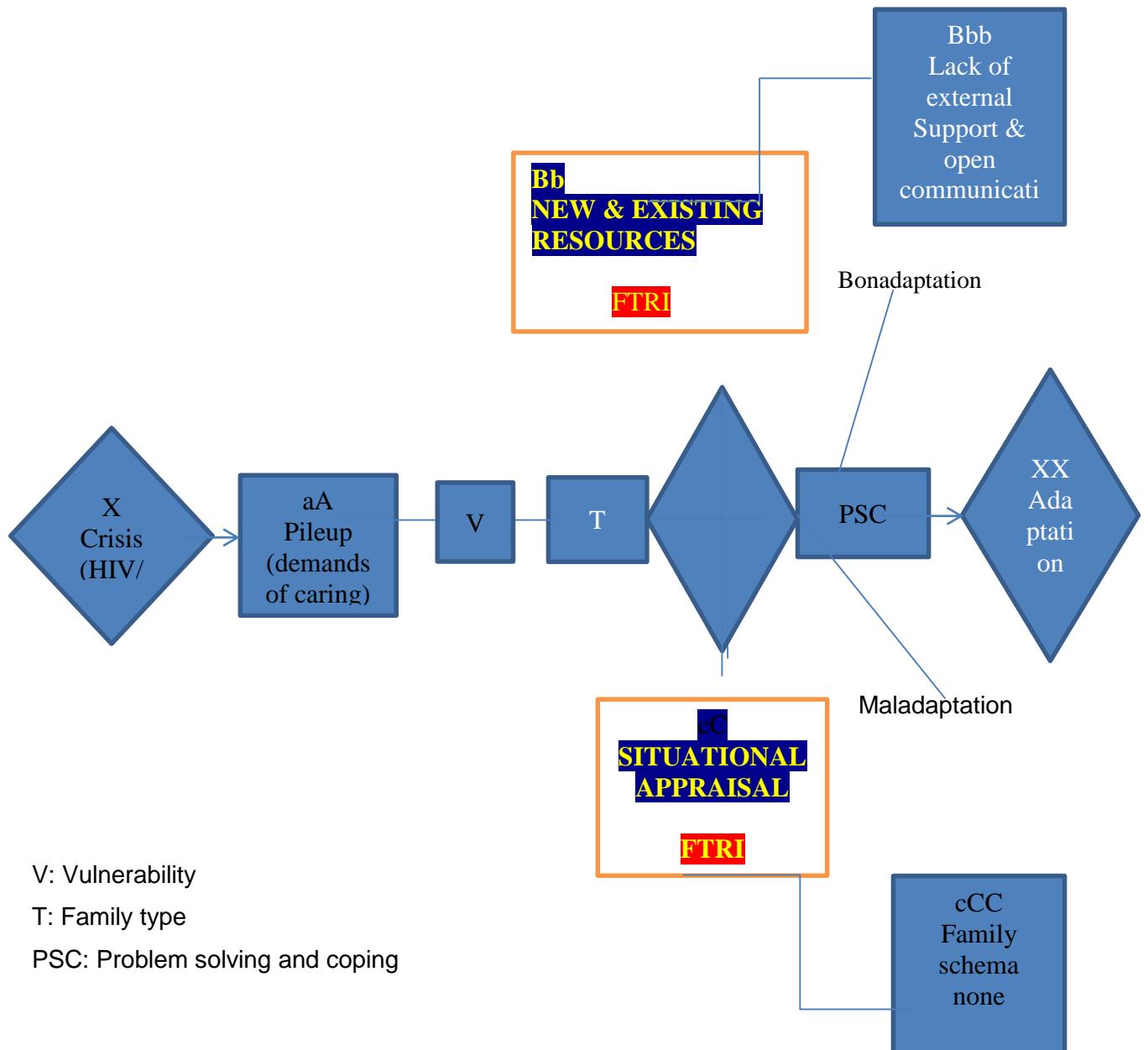
The potential resilient factors among HIV/AIDS affected families were identified by highlighting resilience factors that correlated significantly with family adaptability and changeability scale as per the model of this study. Family Time and Routine Index (FTRI) is the only potential resilience factor identified which correlated with FACI in the case of HIV/AIDS affected

families. This implies that within families, caring for family members physically deteriorating due to HIV/AIDS, spending time together as a family and engaging in common routines is a readily available factor that the family fall back on when facing adversity. In these families togetherness and engaging in certain activities as a family seem to minimize the family's stress brought by the burden of caring.

The highlighted resilience factor implies that parents in the HIV/AIDS affected families create time for each other quite often and it could mean the families engage in certain hobbies or sport activities together regularly, which minimizes stress and enhances coping with the stress of caring for the ailing family members. In addition, it could mean that caregivers in the HIV/AIDS affected families enjoy keeping together and united as a family, creating a joint effort to care for their ailing family members, as well as engaging in certain routines as a collective to increase family resilience.

Figure 2 below gives a diagrammatic representation of the findings of the potential resilient factors used by HIV/AIDS affected families in relation with the existing model of McCubbin Resiliency model of stress, adjustment and adaptation. The insertion made into this model is the factor highlighted in this study as a specific resilience factor (FTRI - family togetherness and connectedness) for the family affected by HIV/AIDS. The factor is the new resource identified for the family resilience and has an appraisal effect for the family adaptation following stress imposed by the experience of being affected by HIV/AIDS.

**Figure 2: McCubbin Resiliency model of stress, adjustment and adaptation for families caring for member physically deteriorating due to HIV/AIDS.**



## **7.5 POTENTIAL RESILIENT FACTORS FOR FAMILIES AFFECTED BY ANY CHRONIC CONDITION BESIDES HIV/AIDS**

In the families affected by any other chronic illness besides HIV/AIDS, the potential resilient factors identified were mainly social support, family hardness qualities as well as togetherness and connectedness as expressed by the scales of Social Support Index (SSI), Family Hardiness Index (FHI) and Family Time and Routine Index (FTRI) respectively.

Social support as the main resilient factor indicates possible family integration into the community and viewing the community as a source of emotional, esteem and network support and having a good relationship with relatives.

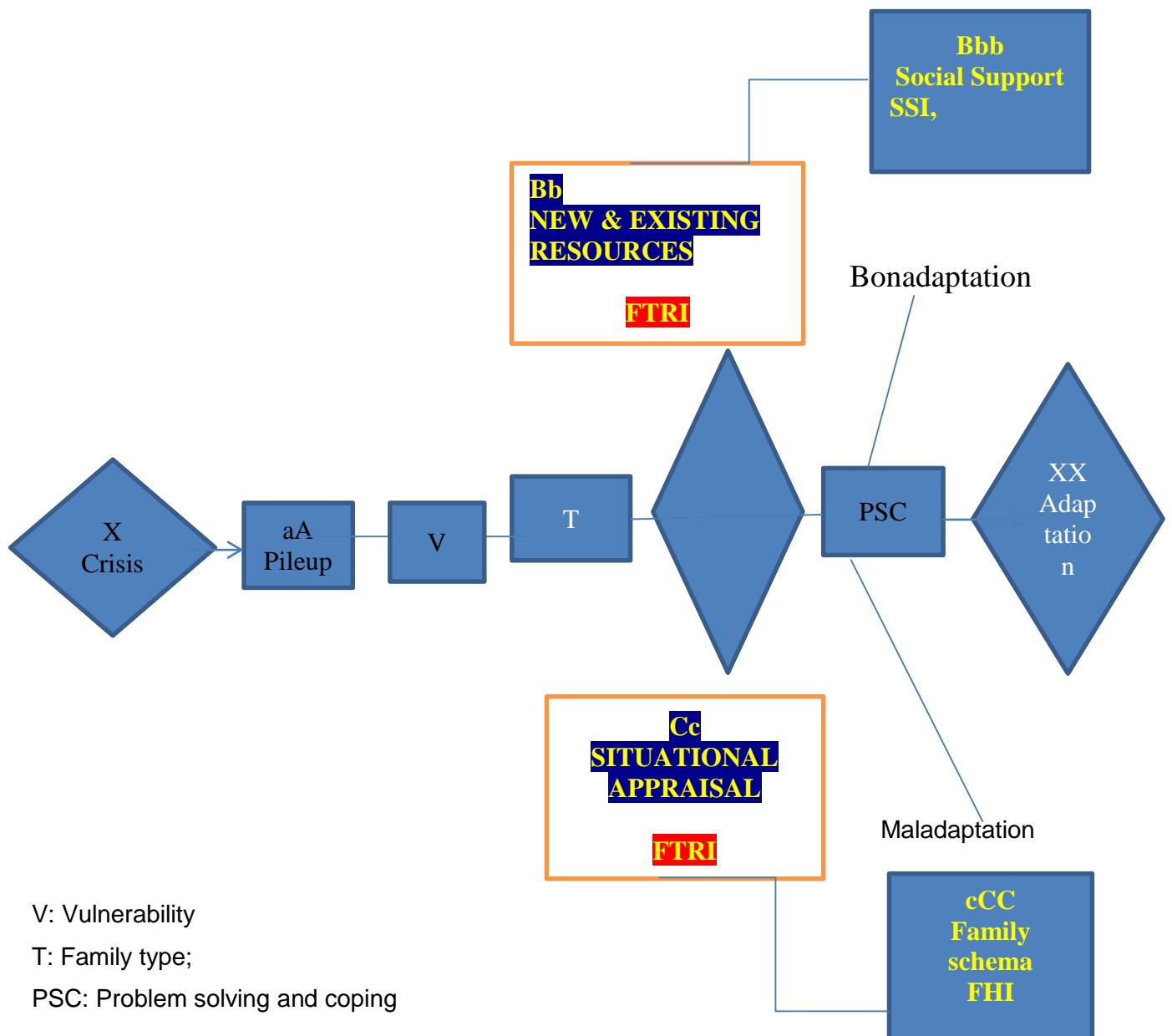
Family hardness as a potential resilience factor in families affected by any other chronic condition could mean that such families have high internal strength and durability when facing stressful situations of the magnitude of caring for their ailing member (see figure 2). As compared to the HIV/AIDS affected families who are more stressed, it could mean that the ailment in this category could still be manageable and not pushing the family to a crisis point where the family loses its capacity to draw strength on its problem solving capacity, typical of the impact of being in a crisis driven environment where problem solving threshold capacity seems unreachable.

Engagement in common family time and routine was also noted as one of the potential resilience factors used by families caring for members physically deteriorating due to any other chronic disorder. This emphasizes that family togetherness, just like in HIV/AIDS affected families, plays an important role in building and maintaining resilience in these families as well. This could mean that a common factor is at play for the two family types, viz. those affected by HIV/AIDS and the other chronic ailments where members could be overly concerned about the wellbeing of family members, and thus find it difficult to get away from home for example to go on holiday because of their caring role.

The diagrammatic outline of the resilient factors for the family affected by other chronic ailments besides HIV/AIDS within the Resiliency model of stress, adjustment and adaptation is shown in Figure 3.

Inserted in the existing model of McCubbin on stress, adjustment and adaptation are specific identified resilience factors of support, togetherness and hardiness which foster family capacity to bounce back. Following care for a member ailing due to any condition other than HIV/AIDS.

**Figure 3: An insertion of resilience factors on McCubbin Resiliency model of stress, adjustment and adaptation, for families affected by any other chronic condition.**

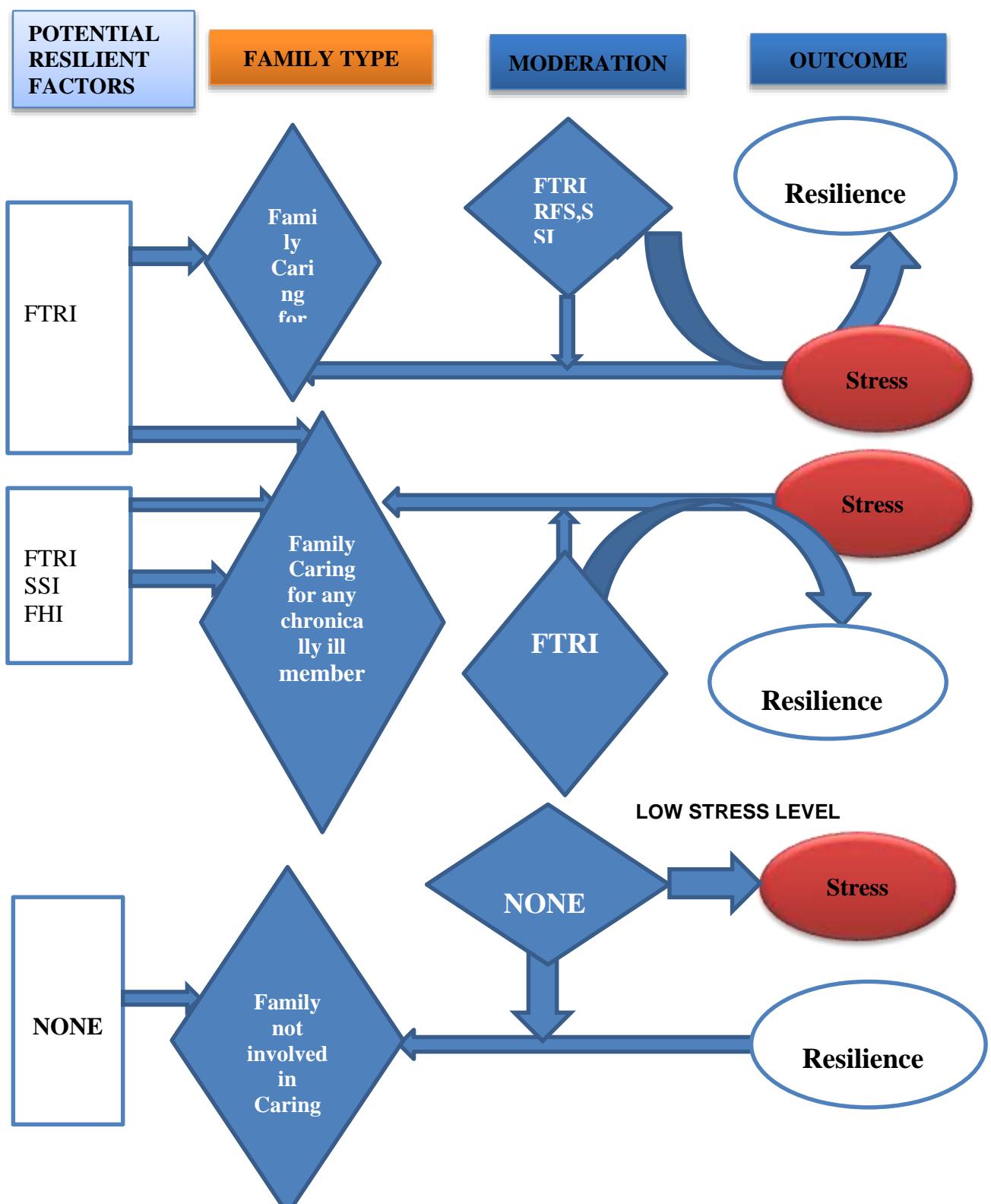


## **7.6 THE MODERATION EFFECT OF RESILIENCE FACTORS ON STRESS ACCORDING TO FAMILY TYPOLOGY**

Families in the caring role experience stress at different levels depending on the condition their ailing family member is suffering from. It appears like stress in families is often determined by the family vulnerability, family type and problem solving and coping abilities. These abilities dictate to the family how they would adapt to their presenting stressor. The study also indicated that stress in the researched families is moderated uniquely by different resilient factors which will be explored in the following discussions.

Figure 4 is the diagrammatic summary of the main findings of the study showing the resilient factors in each family type, as well as the unique resilient factors that moderate stress in each family type. It also illustrates the outcome of adaptation and resilience in relation to the Resiliency Model of Stress, Adjustment and Adaptation, highlighting the resilience factors that moderate stress in the researched families.

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



An exploration of the moderation effect of resilience factors on stress among HIV/AIDS affected families as compared to the two control samples of families was conducted. The analysis indicated that HIV/AIDS affected families rely more on support from within for the family to cope with challenges.

The factors that were found to moderate stress within the HIV/AIDS affected families were identified as FTRI, SSI, RFS, FPSC FCOPES and FHI. This indicates that the mounted stress in these families is mainly moderated by family togetherness and connectedness, both support from the family itself, and social support by relatives and friends, communication, problem solving capacity as well as family hardiness.

The stress moderating factors highlighted in this study will be further explored in the following discussion.

### **7.6.1 Moderation of stress by family togetherness and connectedness**

In this study families see their strength to be the number of times they keep together and do routines in the close family. The factor outlined to be of importance to them was family routine and time spent together (FTRI), whilst in other families, the support by others as well as the problem solving capacity and family hardiness were seen as the factors that make the families bounce back. Family time together and routines are considered reliable indicators of family integration and stability (McCubbin, Thompson & McCubbin, 1996, 2001).

Togetherness allows family units to bridge generations, establish continuity in the present and in the midst of disruptions, and to build a solid foundation of interpersonal supports needed to negotiate major transitions and transformations. Furthermore, togetherness also gives family members an opportunity to update the working members about the progress of the sick member and even allows the fulltime caregivers an opportunity to debrief (Crouter et al., 2004). Sharing a meal together and viewing television as a

family, as well as waiting for the working family members at night to reconnect as a family according to Crouter et al., (2004) is a popular practice among most black families.

### **7.6.2 Social Support as a moderator of stress**

The study highlighted social support as one of the protective and recovery factors used when facing crisis situations. This concurs with the research findings which state that family draws on its supportive relationships to help during its time of crisis (Walsh, 1996; 2003a; Koen, Van Eeden, & Rothmann, 2012). The value of friends and relative support during crisis situation in these families is highly esteemed. In the event where relative and family support is high, stress HIV/AIDS affected families becomes low. On the contrary low family support ignites family stress and disintegration. This therefore, could imply that caring for family members deteriorating due to HIV/AIDS becomes less of a burden when the family has sufficient social support. Wills, Blechman and McNamara (1996) add that interpersonal relationships enhance adaptation through the provision of supportive functions that are of direct or indirect assistance for the coping process. This is in line with the African context that families do thrive on support from others.

Friends and relative support for HIV/AIDS affected families added to effective stress relievers. These families prefer the support of people closer to them such as family members and close friends rather than the support of the entire community. More external support is often seen as having the ability to heighten the stress levels within these families, thus impacting negatively on the ability of these families to withstand adversity with mounting stress and consequently maladaptation.

Maris (1981) holds that support networks extending beyond the family have protective value. Such supportive networks may include friends and other community networks that go as far as the inclusion of the churches or schools. However, in this study social support was found to be common

among close family members, especially HIV/AIDS affected families. This could be somehow associated with the nature of the stressor the family is facing which is often perceived as highly stigmatized by the out-groups.

### **7.6.3 Communication as a stress moderator**

The study established that family problem solving ability and open communication seem to be having a non-counter effect on stress in HIV/AIDS affected families. This indicates that talking about the issues related to the member with HIV/AIDS and trying to openly solve problems related to their condition often evokes stress for both the family and the sick person. Therefore, family stress increases as family problem solving and communication tendencies increase in HIV/AIDS affected families. The stigma attached to HIV/AIDS could be associated with the trend of families avoiding open communication around such issues. However, this contradicts the conclusion by Epstein et al., (2003) which states that open and honest communication is often seen as an important family resilient factor in dealing with stress when facing adversity. Epstein et al., (2003) and Walsh, (2003) hold that positive communication brings clarity during a crisis situation by facilitating open expression and problem solving as a family. They also mention that the clarity along with congruent messages foster effective family functioning.

It is a common practice that African families would prefer to keep their member's status a secret and maintain the information within the family, especially only among the family members to whom the status has been disclosed. Furthermore, family members often believe that talking about their status outside the family borders or circles is a taboo and has the ability to increase stress. Controlled or no communication within these families seems to be both a protective and recovery factor, thus assisting the families to develop effective adaptation skills.

#### **7.6.4 Family Hardiness as a moderating factor**

Family hardiness was also found to be a resiliency factor that buffers against the effects of stress on health. This is in keeping with the findings of Svarasdottir, McCubbin and Kane (2000) that the family is perceived as hardy if it is portrayed as having a sense of control over the end result of the challenges it is experiencing. This means the family can be adaptive by pulling together as a unit to handle the problem as a whole and reframing the crisis as a challenge (McCubbin, McCubbin, Thompson, Han & Allen, 1997). For HIV/AIDS affected families, family hardiness was found to have an escalation effect on the stress levels of the family members. This could imply that the burden of caring for the ailing family member may have a diffusing impact on the internal family strength associated with family hardiness.

### **7.7 CONCLUSION**

Family time and routine Index factor (FTRI) was found in this study to be the common unique resilient factor for both researched families caring for ailing members and the only factor for the HIV/AIDS affected families; The non HIV/AIDS affected families also had social support and hardiness as their resilient qualities.

This common factor was also found to be the only factor that moderated stress for both non-HIV/AIDS affected families and the HIV/AIDS affected families with the latter also having their stress level moderated by friends and relative support (RFS), social support (SSI). FTRI advocates the value of families' connectedness and togetherness; and this fits-in as the 'new and existing resource' component as well as the 'situational appraisal' factor within McCubbin resiliency model of stress adjustment and adaptation (See Figure 4). FTRI is thus the key resilience factor readily utilised by both HIV/AIDS affected families and the non-HIV/AIDS affected families caring for member ailing due to any chronic condition to assist them with resilience during adversity.

Social support is a unique quality for non-HIV/AIDS affected families but a strong moderator for stress for HIV/AIDS affected families which seem to be a valued factor if it could be available. Due to potential fear of being stigmatised, external support seems not to be the preferred option for HIV/AIDS affected families noted in the escalation impact on the stress levels for this group. There is also less keenness to communicate about the condition of the sick member as indicated by the FCOPES and FPSC. This group may only want to communicate internally within the nuclear family.

Family hardiness as a resilience factor for the non HIV/AIDS affected families assist to give the family control of the situation and have a buffer effect on the burden of caring. For HIV/AIDS affected families, family hardiness was found to have an escalation effect on the stress levels of the family members. This could imply that the burden of caring for the ailing family member may have a diffusing impact on the internal family strength associated with family hardiness.

The following chapter will outline the conclusion of the current study so as to inform recommendations for future studies and the development of intervention programmes according to the aim and objectives of this study. The limitations of the present study will also be highlighted.

## **CHAPTER 8**

### **CONCLUSION, RECOMMENDATIONS AND LIMITATIONS**

#### **8.1 INTRODUCTION**

The previous chapters focused on the exploration of stress and dysfunction experienced by families caring for members physically deteriorating due to HIV/AIDS as compared to those families caring for members physically suffering from any other chronic condition, as well as those families not involved with caring for the sick.

The main aim of using the resiliency model to approach the study was to understand and explain the reason why some families recover and others remain at risk and even deteriorate under similar situations (McCubbin & McCubbin, 1993, 2001). The study sought to explore family resiliency factors through which to view the reasons some families navigate through adversities, whereas others do not cope well under similar circumstances. To investigate that, different resilience factors were identified and used to determine their role in helping the caregiving families to bounce back. Specific resilient factors were further assessed and their impact on the moderation of stress within the researched families was explored.

#### **8.2 SUMMARY AND CONCLUSION OF THE FAMILY GROUPS WITH REGARD TO RESILIENCE FACTORS USED AND STRESS MODERATION**

The families in this study have a huge burden of caring for sick members. The burden of the disease especially for the HIV/AIDS affected is such that the families become overwhelmed by the extend of the progression of the condition. The physical deterioration of the sick members includes extreme change on the physique of the person, the cognitive and emotional wellbeing;

and this renders a person to be completely dysfunctional and fully dependent on the family. The study found high stress level among this group of families as compared to the two control groups. The stigma attached to the condition is huge and this often pushes away the extended family (a backbone of support in the African culture) making the burden of caring be borne solely by those who are close to the sick member. The study was aimed at highlighting the inherent qualities in families that make them still cope under such conditions; and comparing HIV/AIDS affected families to those who are burdened by different type of diseases. The HIV/AIDS affected have been identified to have multiple caring burdens because of the disease itself and how its progression impacts on the family as well as how the society adds onto the burden by discriminating against the sufferers of the disease and their caregivers.

The findings in the study showed that families' capacity to rally around each other has given them the strength to bounce back in the adversity. The trend seemed to be that mostly the affected families are in the low income bracket making caring become very burdensome; and in other many cases, the elderly seem to be the ones caring for the younger infected children with its own complications of parenting. Usually in African families adults have always been the ones caring for the sick in families; but it was always caring for the elderly. In the non-HIV/AIDS affected families caring for sick members with other chronic conditions the younger members were found to be the ones caring for the sick who were mostly older members of the family. Family togetherness and connectedness seemed to be the key quality to help both family types cope with the role reversal situations that emerged in the caregiving processes. The FTRI resilience factor is thus the key appraisal component that emerged for these groups for bon-adaptation in line with ABCX model on adaptability

Social support was found to add value and resilience to the caring families. For HIV/AIDS affected families support emerged only as a stress moderating factor whilst togetherness and connectedness emerged both as stress moderating factor and expressed as resilience qualities for the families. Stress

in this group was found to be escalated by open communication and hardiness. For the non-HIV/AIDS affected families who cared for members suffering from other chronic conditions connectedness was key as well as resilience factors of support and hardiness.

Family problem solving and communication seems to be a more useful resilient factor for families affected by any other chronic illness than those families affected by HIV/AIDS. This means that families caring for members suffering from any other chronic illness would probably be more open in terms of family problem solving and communication. Talking about the diagnosis and solution of the problems the sick family member is facing, within and outside the family is welcome and encouraged in this group. This could include seeking solutions from community members, neighbours etc. This could possibly be the unidentified antidote to stress level within the family, hence the reported low stress level in this family group in the study.

In conclusion, HIV/AIDS affected families navigate through their stress by using multiple resources and factors such social collectivism, which includes social support and togetherness. Family strength also facilitates bond-adaptation and in turn works together in collaboration with social support and family togetherness in building family resistance, family resilience and mediating stress in the affected families. Moreover, controlled communication came out to be very helpful in keeping the secret of the family within the bounds of the family and bringing members closer to each other. Demographic characteristics highlighted within the caregiving complexity in this study call for more emphasis for further research to explore ways to support caregivers in lessening the burden of caring for the sick family members.

### **8.3 LIMITATIONS OF THE STUDY**

It is important to highlight that the findings of this research should be understood within the context of the following limitations:

- The Relative Stress Scale is a burden scale initially used to measure individual stress levels and it is a self-report scale. In this study the scale was altered and used as improvise to measure family stress levels. Self-report measures can have some challenges in the validity of the results.
- The sample size initially proposed was not achievable due to the difficulty in accessing families affected by HIV/AIDS. Higher numbers for all the family groups would have been ideal.
- Access to other ethnic groups was difficult for the researcher with subsequent possible compromise on the generalizability of the results to other cultural groups in Limpopo Province.
- The study used the quantitative method of data collection and did not engage any qualitative approaches. This could have brought some richness from the in-depth discussions on the different understanding of the feelings and meanings of coping strategies and expression of burden of caring for the sick by the families.

### **8.4 RECOMMENDATIONS FOR FURTHER RESEARCH**

The study could be important in adding value and knowledge in terms of understanding stress experienced by caregivers in relation to the kind of condition the family members suffer from. The study also identified that HIV/AIDS affected families experience high stress levels as compared to other researched families. Furthermore, it highlighted family resilience and those resilient factors that moderate stress in HIV/AIDS affected families. The demographic dynamics within the affected families and their role in building

resilience and moderating stress were understood within different families.

On the basis of the above findings the following are therefore recommended:

- Data collection was quantitative in nature and no in-depth discussions were done to understand the family's feelings in the caregiver role for the infected members. Future research could benefit from including components of qualitative investigations to have in-depth understanding of how caregiving of ailing members impact on the families.
- The dynamics of the unique significance of self-expressed need for togetherness as a resilient factor in the family affected by HIV/AIDS as opposed to social support which emerged only as stress moderator in such families need further investigation within the context of stigmatization effect of HIV/AIDS within the African culture.
- HIV/AIDS stigma within families appears to be still an impending issue perpetuating secrecy and non-communication around HIV disclosure. Research on open communication/disclosure and the need for redirecting the abundant collectivistic supportive, a brand for the African culture, need to be investigated for implementation in the intervention among HIV/AIDS affected families.
- The trend of infections seems to demonstrate that lately there are more HIV/AIDS orphans than before. Grandparents have taken more caregiving roles than other groups. The African role of being brought up by grandparents is becoming burdened by raising those children within the burden of an ailment that is regarded as intense in nature and quite stigmatized to attract the supportive inherent nature of the African culture within the extended family and community/neighborliness context. Future research regarding resilience on HIV/AIDS affected children and the impact of such caregiving role in contrast to the African use of grandparents for the normal child rearing role for the ageing population could be beneficial.
- The high stress level among HIV/AIDS affected families point to a need to engage families in stress management processes as well as

the awareness of HIV/AIDS stigmatization effect on caregivers. Future research could focus on the effect of stress management and awareness campaigns for lessening stigma on the families to foster family wellbeing to be able to continue with care provision for the infected family members.

- High stress level was also indicated as a function of caring for young sick family members as well as caring within low socio-economic conditions shown by stress elevation with the care of a sick breadwinner, and also in circumstances where family income was negligible.
- Further research is needed to highlight the dynamics and the relationship with stress elevation around the new trend of HIV/AIDS infection of the younger age group as well as the economic burden or the impact of lack of resources in caring for the infected.
- More in-depth research could also be done on the impact of caregiving by differentiating between caregiving of the sick family members who suffer from specific conditions such as diabetes mellitus, hypertension, heart conditions, cancers etc.; as well as focussing on the dynamics between stigmatisation, stress moderation and resilience of families using more diverse families engaging in various caregiving situations of sick family members within various ecological and socio economic conditions.

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## APPENDIX A: QUESTIONNAIRE

### Biographical Information

All information in this questionnaire is strictly confidential and your information will be anonymously processed. Please cross the box most appropriate to you, or complete the statement in the space provided:

1. Living in..... (Town or city)

2. Marital status (please tick the box which best describes your current status and fill in the number of years)

	Single	Married	Divorced	Widowed
Tick				
No of years				

How long have you been married to your current partner? ..... Years

3. Family composition (Clearly indicate which family member will complete the questionnaires)

			CHILD (position in the family )				
	Self	Spouse	1	2	3	4	5
Age							
Gender							

Is there anyone else who lives permanently with you in your home?

No

Yes

Please give details: .....

### 4. Job, Education, Income and Home Language

Please give some detail about **your** job (e.g. Temporary/permanent? Nature of work?)

.....  
.....

Please give a short description of **your partner's** work (e.g. Temporary/permanent? Nature of work?) .....

### 5. What is the age of the sick family member?

### 6. What is the position held by the sick member in the family?

### 7. What is the gender of the sick member of the family?

### 8. What is your highest level of education?

Primary school  High school   
Diploma  Degree   
Others: .....

**Sick family member's level of education**

Primary school  High school  
 Diploma  Degree  
 Others: .....

**9. What is your family's estimated gross income per year?**

- Less than R20 000  
 R21 000 - R40 000  
 R41 000 - R60 000  
 R61 000 - R80 000  
 R81 000 - R100 000  
 R101 000 or more

**10. What is your home language?**

- Sepedi  
 XiTsonga  
 TshiVenda  
 IsiNdebele  
 Other (specify).....

**APPENDIX B : RESILIENCE SCALES**
**SSI**

	<b>SD</b>	<b>D</b>	<b>N</b>	<b>A</b>	<b>SA</b>	<b><i>Official use</i></b>
Please rate the following statements as they apply to your family as hereunder :						
Strongly Disagree(SD)						
Disagree(D)						
Neutral (N)						
Agree (A)						
Strongly Agree(SA)						
1. If I had an emergency, even people I do not know in this community would be willing to help						
2. I feel good about myself when I sacrifice and give time and energy to members of my family						
3. The things I do for members of my family and they do for me make me feel part of this very important group						
4. People here know they can get help from the community if they are in trouble						
5. I have friends who let me know they value who I am and what I can do						
6. People can depend on each other in this community						
7. Members of my family seldom listen to my problems or concerns; I usually feel criticized						
8. My friends in this community are a part of my everyday activities.						
9. There are times when family members do things that make other members unhappy						
10. I need to be very careful how much I do for my friends because they take advantage of me.						
11. Living in this community gives me a secure feeling						
12. The members of my family make an effort to show their love and affection for me.						
13. There is a feeling in this community that people should not get too friendly with each other						

14. This is not a very good community to bring children up in						
15. I feel secure that I am as important to my friends as they are to me						
16. I have some very close friends outside the family who I know really care for me and love me						
17. Member(s) of my family do not seem to understand me; I feel taken for granted						

## 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.

Please rate the following statements as they apply to <u>how your family cope</u> as hereunder :	<b>SD</b>	<b>D</b>	<b>N</b>	<b>A</b>	<b>SA</b>	<b><i>Official use</i></b>
Strongly Disagree(SD) Disagree(D) Neutral (N) Agree (A) Strongly Agree(SA)						
1. Sharing our difficulties with relatives						
2. Seeking advice from relatives						
3. Doing things with relatives (get togethers)						
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						

**FPSC**

When our family struggles with problems or conflicts which upset us, I would describe my family in the following way:	False	Mostly False		
1. We yell and scream at each other	0	1		
2. We are respectful of each others' feelings	0	1		
3. We talk things through till we reach a resolution	0	1		
4. We work hard to be sure family members are not hurt, emotionally or physically	0	1		
5. We walk away from conflicts without much satisfaction	0	1		
6. We share with each other how much we care for one another	0	1		
7. We make matters more difficult by fighting and bring up old matters	0	1		
8. We take time to hear what each other has to say or feel	0	1		
9. We work to be calm and talk things through	0	1		
10. We get upset, but we try to end our conflicts on a positive note	0	1		

**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 .....	<i>False</i>	<i>Mostly False</i>	<i>Mostly True</i>	<i>True</i>	<i>Not Applicable</i>	
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						
16. 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						

## F-COPES

### DIRECTIONS

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

**Second**, decide how each statement will describe 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	2	3	4	5
Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree

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

- \_\_\_\_ 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 programmes 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 favours 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
- \_\_\_\_ 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 neighbours
- \_\_\_ 30. Having faith in God
- \_\_\_ 31. Having faith in ancestors

## 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 aspect is happening right now.

Now				
In my family...				
1. In our family it is easy for everyone to express his/her opinion.				
2. It is easier to discuss problems with people outside the family than with other family members.				
3. Each family member has input in major family decisions.				
4. Family members discuss problems and feel good about the solutions.				
5. In our family everyone goes his/her own way.				
6. Family members consult other family members on their decisions.				
7. We have difficulty thinking of things to do as a family.				
8. Discipline is fair in our family.				
9. Family members feel closer to people outside the family than to other family members.				
10. Our family tries new ways of dealing with problems.				
11. In our family, everyone shares responsibilities.				
12. It is difficult to get a rule changed in our family.				
13. Family members avoid each other at home.				
14. When problems arise, we compromise.				
15. Family members are afraid to say what is on their minds.				
16. Family members pair up rather than do things as a total family.				

## FTRI

### Instructions

**First**, read the following statements and decide to what extent each of the routines listed below is false or true about your family: **False (0), Mostly False (1), Mostly True (2), True (3)**. Please circle the number (0, 1, 2, 3) which best expresses your family experiences.

**Second**, determine the importance of each routine to keeping your family together and strong: **NI = Not Important, SI = Somewhat Important, VI = Very Important**. Please circle the letters (NI, SI, or VI) which best express how important the routines are to your family. If you do not have children, relatives, teenagers, etc., please circle NA = Not Applicable.

Routines	False	Mostly False	Mostly True	True	How Important is keeping the Family Together and United			
					Not <u>Important to family</u>	Somewhat	Very	Not applicable
1. Parent(s) have some time each day for just talking with the children	0	1	2	3	NI	SI	VI	NA
2. Working parent has a regular play time with the children after coming from work	0	1	2	3	NI	SI	VI	NA
3. Working parent takes care of the children some time almost every day	0	1	2	3	NI	SI	VI	NA
4. Non-working parent and children do something together outside the home almost every day (e.g., shopping, walking, etc.)	0	1	2	3	NI	SI	VI	NA
5. Family has a quiet time each evening when everyone talks or plays quietly	0	1	2	3	NI	SI	VI	NA
6. Family goes some place special together each week	0	1	2	3	NI	SI	VI	NA
7. Family has a certain family time each week when they do things together at home	0	1	2	3	NI	SI	VI	NA
8. Parent(s) read or tell stories to	0	1	2	3	NI	SI	VI	NA

the children almost every day								
9. Each child has some time each day for playing alone	0	1	2	3	NI	SI	VI	NA
10. Children/teens play with friends daily	0	1	2	3	NI	SI	VI	NA
11. Parents have a certain hobby or sport they do together regularly	0	1	2	3	NI	SI	VI	NA
12. Parents have time with each other quiet often	0	1	2	3	NI	SI	VI	NA
13. Parents go out together one or more times a week	0	1	2	3	NI	SI	VI	NA
14. Parents often spend time with teenagers for private talks	0	1	2	3	NI	SI	VI	NA
15. Children have special things they do or ask for each night at bedtime (e.g. story, good-night kiss, hug, etc.)	0	1	2	3	NI	SI	VI	NA
16. Children go to bed at the same time almost every night	0	1	2	3	NI	SI	VI	NA
17. Family eats at about the same time each night	0	1	2	3	NI	SI	VI	NA
18. Whole family eats one meal together daily	0	1	2	3	NI	SI	VI	NA
19. At least one parent talks to his or her parents regularly	0	1	2	3	NI	SI	VI	NA
20. Family have regular visits with the relatives	0	1	2	3	NI	SI	VI	NA
21. Children/teens spend time with grandparent(s) quite often	0	1	2	3	NI	SI	VI	NA
22. We talk with/ write to relatives usually once a week	0	1	2	3	NI	SI	VI	NA
23. Family checks in or out with each other when someone leaves or comes home	0	1	2	3	NI	SI	VI	NA
24. Working parent(s) comes home from work at the same time each day	0	1	2	3	NI	SI	VI	NA

25. Family has certain things they almost always do to great each other at the end of the day	0      1      2      3	NI      SI      VI      NA
26. We express caring and affection for each other daily	0      1      2      3	NI      SI      VI      NA
27. Parent(s) have certain things they almost always do each time the children get out of line	0      1      2      3	NI      SI      VI      NA
28. Parents discuss new rules for children/teenagers with them quite often	0      1      2      3	NI      SI      VI      NA
29. Children do regular household chores	0      1      2      3	NI      SI      VI      NA
30. Mothers do regular household chores	0      1      2      3	NI      SI      VI      NA
31. Fathers do regular household chores	0      1      2      3	NI      SI      VI      NA
32. Teenagers do regular household chores	0      1      2      3	NI      SI      VI      NA

## RSS

### Instructions

**First**, read the following questions and decide to what extent each of the routines listed below is false or true about your family: **Not at all (0), Sometimes (1), Most of the times (2), All the times(3) To a higher degree (4)**. Please circle the number **(0, 1, 2, 3 and 4)** which best expresses your family experiences.

1. Does your family feel they can no longer cope with the situation?	0 1 2 3 4
2. Does your family ever feel they need a break?	0 1 2 3 4
3. Does your family ever get depressed by the situation?	0 1 2 3 4
4. Does your family ever suffer from health related symptoms?	0 1 2 3 4
5. Does your family worry about accidents happening to your family member?	0 1 2 3 4
6. Does your family ever feel that there will be no end to the problem?	0 1 2 3 4
7. Does your family find it difficult to get away on holiday?	0 1 2 3 4
8. How much have your family's social life been affected?	0 1 2 3 4
9. How much has the household routine been upset?	0 1 2 3 4
10. Is your family's sleep interrupted by caring for the sick member?	0 1 2 3 4
11. Has your family's standard of living been reduced?	0 1 2 3 4
12. Does your family member ever feel embarrassed by the sick member's illness?	0 1 2 3 4
13. Is your family at all prevented from having visitors?	0 1 2 3 4

14. Do members of your family ever get cross or angry with the sick member?	0 1 2 3 4
15. Does your family ever feel frustrated at times with caring for the sick member?	0 1 2 3 4