

Families in crisis: A comparative hermeneutic study of the impact of cancer and HIV/AIDS on families.

Eugene du Plessis

15 December 2002

Submitted in partial fulfilment of the requirements for a Master of Arts (Clinical Psychology) degree, in the School of Psychology, University of Natal. Unless specifically indicated to the contrary, this thesis is the result of my own work.

Acknowledgements

First and foremost I would like to thank all the participants for allowing me access to their very difficult and personal experiences. My mother, Deirdre du Plessis, has also showed me invaluable support and assistance during the writing of this thesis, despite her own struggle with cancer. Mr Konrad Schrenk's financial assistance during my Masters degree has been most generous and kind. Finally I wish to thank my supervisor, Mr Douglas Wassenaar. Not only your criticism and guidance with regards to my thesis, but also the times you listened to me during this difficult period of my life, have been of inestimable value.

Abstract

This study employed a qualitative hermeneutic methodology to compare and explore the stress faced by families caring for a family member with cancer or HIV/AIDS. Four 'Indian' families, two with a family member with cancer and two with a family member with HIV/AIDS, were purposively sampled through NGOs in Pietermaritzburg and Durban. Generally it appeared that the illnesses brought about a range of stressors in families including financial and care-related stressors, role changes, difficulties accessing medical treatment, uncertainty and the psychological responses of family members. The impact of these on families was mediated by the families' abilities, social support, a variety of meaning factors and stigma. It did however, appear that families caring for a family member with HIV/AIDS had to cope with several additional burdens including coping with a more prolonged and variable period of illness, fears of infection, increased difficulties accessing medical treatment, less social support and stigma.

Contents

1	Introduction.....	1
2	Literature Review.....	1
2.1	Cancer and its impact on individuals.....	1
2.2	HIV/AIDS and its impact on individuals.....	6
2.3	The impact of cancer and HIV/AIDS on families	13
2.3.1	Increased burdens related to caring for the ill family member	15
2.3.2	Sexual and reproductive difficulties	17
2.3.3	The uniqueness of HIV/AIDS.....	18
2.3.4	Psychopathology related to caring for a family member with cancer or HIV/AIDS.....	19
2.4	Theories of family stress	20
3	Method	26
3.1	Design	26
3.2	Participants.....	30
3.3	Equipment and Measures.....	32
3.4	Procedure	34
4	Results.....	36
4.1	Families caring for a family member with cancer	36
4.1.1	A family where the breadwinner is the patient: The Mutara family.....	36
4.1.1.1	Stressors	37
4.1.1.2	Mediating factors	40
4.1.1.3	Summary	41
4.1.2	A family where the caregiver is the patient: The Naran family.....	42
4.1.2.1	Stressors	43
4.1.2.2	Mediating factors	48
4.1.2.3	Summary	52
4.2	Families caring for a family member with AIDS	53
4.2.1	A family where the breadwinner is the patient: The Govender family.....	53
4.2.1.1	Stressors	54
4.2.1.2	Mediating factors	59
4.2.1.3	Summary	64
4.2.2	A family where the caregiver is the patient: The Moodley family	65
4.2.2.1	Stressors	66
4.2.2.2	Mediating factors	71
4.2.2.3	Summary	73
5	Discussion.....	74
5.1	Discussion of main findings.....	74
5.1.1	The impact of the chronic illness on the families	75
5.1.2	The impact of caring for a family member with cancer.....	79
5.1.3	The impact of caring for a family member with HIV/AIDS	81
5.2	Limitations of this study	89
5.3	Implications of the findings	92
6	Conclusion	93
7	References.....	95
8	Appendices.....	106
8.1	Appendix A: Consent form 1	106
8.2	Appendix B: Consent form 2	107
8.3	Appendix C: Interview guide.....	108

8.4 Appendix D: Coding themes..... 109

1 Introduction

Cancer and HIV are illnesses affecting the lives of many South Africans. Families are often the primary source of care through the course of these illnesses. Caring for an ill family member is demanding and places many burdens on families. While there is a large body of literature examining the impact of HIV/AIDS on families, much of this is based on North American and Western European populations which, as will be discussed in later chapters, differ from local populations in terms of infection patterns and access to medical resources. There is thus still a need for South African research exploring the impact of HIV on families. This study employs a hermeneutic explorative and comparative methodology to compare the impact that caring for a family member with HIV/AIDS had on two families, to the impact that caring for a family member with cancer had on two families. This methodology highlights both the unique and common ways that these illnesses may affect families.

2 Literature Review

The physical and psychological impact of cancer and HIV/AIDS on affected individuals can be dramatic. This will be explored before commencing with a discussion of the impact that these illnesses may have on families. This will highlight both the common and unique aspects of these illnesses. Several theoretical models which attempt to describe families' responses to stressful situations will then be explored.

2.1 Cancer and its impact on individuals

Cancer is a disease with a high degree of public prominence. It may be the most researched chronic illness, having accumulated centuries worth of literature referring to it since initially

being named by the Greek physician Hippocrates (CANSA, 1998). Campaigns addressing breast cancer awareness and anti-smoking have often used celebrity spokespeople and have raised cancer awareness in the general public. They have succeeded in elevating the significance of cancer so that it is debated and addressed at both a public and a political level. Cancer is thus a topical and important issue.

As a disease, cancer intimately affects the lives of millions of people around the world. It has been estimated that there were over 10 million cases of cancer and approximately 7 million cancer related deaths worldwide in the year 2000 (Globocan, 2002). The most common cancer in 1990 was lung cancer, accounting for 18% of cancers (Parkin, Pisani & Ferlay, 1999). Because lung cancer and several other cancers have been linked to tobacco smoking and chewing, it has been estimated that 20% of all cancers could be prevented by eliminating these practices (Pisani, Parkin, Bray & Ferlay, 1999).

Many South Africans are affected by cancer. The National Cancer Registry (2001) reports that between 1993 and 1995, approximately a quarter of all South Africans younger than 74 had experienced some form of cancer (excluding basal and squamous cell skin cancers), at some point in their lives. It is thus likely that if a person is not directly affected by cancer, they may know someone, possibly a relative or a close friend, who has been affected.

Cancer affects people of all ages. Nevertheless, while cancer affects the lives of many young people, the statistics of the National Cancer Registry (2001) suggest that the incidence of cancer increases with age. Thus, while it must not be forgotten that many people with cancer are young and in the economically productive period of their lives (Schlebusch, 1999), the incidence of cancer appears to be higher among the elderly.

The term 'cancer' is used to refer to over 200 conditions characterised by abnormal and excessive cell division (Cairns, 1978; CANSA, 1998; Hughes, 1987; Schlebusch, 1999). Each cancer is associated with specific tissues and sites of origin. A multifactorial aetiology, which includes various carcinogenic agents and the level of genetic predisposition, appears to be involved (Hughes, 1987; National Cancer Registry, 2001). Cancer originates in single cells and may, over the course of what is usually many years, develop into a tumour (Cairns, 1978; Hughes, 1987). CANSA (1998) reports that many cancers only become symptomatic after 10 to 30 years.

There are two different types of tumours (CANSA, 1998). Tumours are either benign (tumours which do not invade surrounding tissue) or malignant (tumours which do invade surrounding tissue). If left untreated, malignant tumours may spread or 'metastasize' via the blood or lymph system to other parts of the body. This leads to the development of secondary tumour sites or 'metastases'. With both types of tumours, the cells continue to divide and may eventually cause death as they interfere with normal body functioning.

Several treatments have been developed for cancer. The choice of treatment is dependent on the stage at which the cancer was discovered and the nature of the particular cancer. If the cancer was discovered before it metastasized, then there is a much higher chance that it can be cured (Cairns, 1978; CANSA, 1998). Treatment is then tailored to be curative (Cairns, 1978; Hughes, 1987). This is usually drastic and often has marked side effects. If the cancer is very advanced then the treatment is gentler and is designed to be palliative. The aim is then to prolong life, relieve symptoms and reduce the suffering of the patient. The various

treatment options available to oncologists include surgery, radiotherapy, chemotherapy, hormonal therapy and bone marrow transplants.

Surgery, radiotherapy and chemotherapy are the three main forms of treatment. Surgery is often the treatment of choice when tumours are benign or have not yet metastasized (Cairns, 1978; CANSA, 1998). It may however, radically alter the person's appearance (for example mastectomy) or body functioning (for example gastrectomy) (Hughes, 1987; Jacobsen & Holland, 1989; Schlebusch, 1999). If the tumour has metastasized then it is often treated with either radiotherapy or chemotherapy.

Radiotherapy involves the administration of radiation into the tumour with the intention of damaging cancer cells (Holland, 1989; Hughes, 1987; Schlebusch, 1999). However, many healthy cells are also damaged in the process. Side effects may include gastrointestinal symptoms (such as diarrhoea, nausea and vomiting), hair loss in the radiation field, haematological disorders (such as anaemia and thrombocytopenia (Holland, 1989)), immunosuppression, sexual arousal difficulties, fertility problems and neurological symptoms (such as headaches and impaired memory).

The aim of chemotherapy is similar to that of radiotherapy. Chemotherapy involves the administration of cytotoxic drugs that also kill both healthy and cancerous cells (Holland & Lesko, 1989; Hughes, 1987; Schlebusch, 1999). Side effects include gastrointestinal symptoms (such as nausea and diarrhoea), fatigue, hair loss, sexual arousal difficulties, fertility problems, lowered immune system functioning, neurological symptoms (such as peripheral neuropathy, mood changes and impaired cognition) and secondary malignancies. Oncologists may also choose to use several other treatments to treat particular cancers.

Certain cancers may warrant unique treatments. Cancers such as prostate or breast cancer have a hormonal association and may be treated by manipulating the patient's hormonal levels (Holland & Lesko, 1989). This may lead to changes in the patient's secondary sexual characteristics. These changes may include changes in the body's hair and fat distribution as well as breast engorgement in men and hoarseness and masculinisation in women. Bone marrow transplantation is the treatment of choice for various haematological conditions (Lesko, 1989). Complications include sterility, graft rejection and infection. Thus, both cancer and its treatment can significantly affect an individual's life.

The diagnosis of cancer has a dramatic impact and can be distressing for patients. Schlebusch (1999) reports that 51% or more of cancer patients experience some or other form of psychopathology. In a recent study investigating the levels of depression, anxiety and hopelessness in patients recently diagnosed with cancer in Pietermaritzburg, Pillay (2001) matched 50 cancer patients with a physically healthy control group. It was found that the cancer patients experienced more than double the anxiety symptoms, depressive symptoms and hopelessness than the control group. Schlebusch (1999) reports that up to 68% of cancer patients develop an adjustment disorder with anxiety or depression. A further 13% develop a major depression and 8% develop delirium. Other estimates suggest that approximately 25% of patients meet the diagnostic criteria for either a major depressive disorder or an anxiety disorder (Jones, 2001). Yet another estimate is that 15% to 20% of cancer patients may have a depressive disorder (Berard, 2001). Cancer patients may also experience distress in a number of other ways.

Many cancer patients may experience difficulties related to their body image (Schlebusch, 1999). Schlebusch (1990) defines body image as the sum total of a person's mental representation of their body and its constituent parts. As has already been noted, several cancer treatments may radically alter the person's appearance or impact on their body's functioning. Losing a breast, needing to rely on a colostomy bag, becoming infertile, losing sexual functioning or changing hormonal levels, can dramatically change the person's view of themselves. They may struggle to accept the changes in their body and experience a significant amount of distress in coming to terms with these changes.

Living with cancer may be very difficult for many people due to the nature and meaning of both the disease and its treatments. However, it must not be forgotten that many people with cancer are treated successfully (CANSa, 1998; Jordaan, 1982; Schlebusch, 1999). Thus, there is hope for the millions of cancer patients around the world. HIV/AIDS differs significantly from cancer in this respect, as there is currently no cure available.

2.2 HIV/AIDS and its impact on individuals

HIV/AIDS has had a dramatic impact on the world in the last 20 years. Not only have millions of people been infected with HIV, but the threat of infection has prompted global concerns surrounding practices such as sexual behaviour, intravenous drug abuse, blood transfusions and needle stick injuries to medical personnel. Furthermore, there has been much debate in the media and government, especially in South Africa, surrounding issues such as the treatment and aetiology of AIDS. It has thus become a prominent issue in South Africa and the rest of the world.

From the outset there has been a marked contrast between the First and Third World populations affected by HIV/AIDS. In 1981, it first came to prominence in the USA as a disease affecting male homosexuals (Evian, 1993; Good, 1984; Joubert, 1991). A few years later it was discovered in Central Africa in a heterosexual population. This pattern of infection appears to have been maintained (Joubert, 1991). In the developed world, many of those infected by HIV are male homosexuals or intravenous drug users. In the developing world however, the disease appears to predominantly affect heterosexuals. The implication of this is that much of the literature on HIV/AIDS and its impact in the developed world refers to a different infection population to that of the developing world, with regards to both culture and sexual practices.

Despite HIV/AIDS being a global problem, its impact on the Third World, and especially Sub-Saharan Africa has been dramatic. Approximately 96% of people infected with HIV/AIDS live in the developing world (Allen, Simelela & Makubalo, 2000). Furthermore, approximately 70% of people infected with HIV live in Sub-Saharan Africa. In South Africa, statistics derived from women attending antenatal clinics suggests that in 1999 22,4% of these women were infected. In KwaZulu Natal 32,5% were seropositive. This was the highest level of infection in South Africa. The Department of Health (2000) has acknowledged that the HIV epidemic in South Africa is one of the fastest growing epidemics in the world. HIV/AIDS has thus had a considerable impact on this country and its people.

HIV has a profound, persistent and progressive impact on the body's immune system (in particular the 'helper T' or 'CD4 T' cells) (Good, 1984; Tross, 1989; Tyckoson, 1985). The body's ability to fend off infections is thus lowered and it becomes prone to repeated infections from opportunistic viruses, fungi, bacteria and protozoa (Good, 1985; Tross, 1989).

Typical opportunistic infections include herpes simplex, Candida and hepatitis B. In South Africa TB is often an early opportunistic infection (Schaaf, Cotton, DeVilliers & Donald, 2000). While other diseases may also affect the immune system (including several forms of cancer), the impact of HIV on the immune system is more profound and progressive.

Patients with HIV are also prone to developing malignant conditions (Good, 1984). Kaposi's sarcoma is the most common cancer associated with HIV (Tross, 1989). Non-Hodgkin's lymphoma is the most common haematological malignancy associated with HIV (Brittain, 2000). People with HIV are 14 times more likely to develop low-grade lymphoma and 350 times more likely to develop intermediate to high-grade non-Hodgkin's lymphoma, than the general population. Thus, malignancies are a matter of concern to HIV patients.

Within approximately 5 years of becoming infected, individuals may develop AIDS (Tross, 1989). Healthy HIV negative people have CD4 cell counts between 700 and 1300 per millilitre of blood (AIDS Foundation of South Africa, 2000). As HIV infection progresses, CD4 cells are gradually lost and the patient's immunological functioning deteriorates. Once this count drops below 200, they are diagnosed with Acquired Immune Deficiency Syndrome (AIDS). This is characterised clinically by a range of severe symptoms such as severely impaired immunological functioning, fatigue, diarrhoea, weight loss, fever, generalised aches and pains and enlarged lymph nodes. Neurological complications such as mental and/or motor slowing, forgetfulness and loss of concentration may also arise in as many as a third to three quarters of patients. These symptoms may eventually culminate in the AIDS Dementia Complex (ADC) (Tross, 1989). Generally health problems become progressively more debilitating for infected individuals, necessitating regular medical check-ups to monitor and manage opportunistic infections (Evian, 1993).

While awaiting the development of a possible vaccine for HIV (Galloway, 2000), the only treatments that are currently available for the direct treatment of HIV/AIDS are palliative antiretroviral therapies. These are accompanied by many unpleasant side effects such as neurological difficulties, lactic acidosis, raised cholesterol, myelosuppression, pancreatitis, allergic reactions and insulin resistance, depending on the drug being used (Lachman, 1990; Miller, 2000). These side-effects negatively affect the quality of life of treated individuals.

Antiretroviral drugs are however, costly. Citing this as a reason, the current policy of the Department of Health of South Africa (2002) is to not provide antiretroviral drugs at public healthcare facilities. They argue that even at an 80% to 90% reduction in the cost of these drugs, they would still be unaffordable. Their current policy (Department of Health, 2000; 2002) is to address the HIV/AIDS epidemic through activities such as funding safe-sex education programmes and encouraging home-based care for people living with AIDS. This policy has been challenged by the Treatment Action Campaign (TAC).

The TAC, a local non-governmental organisation (NGO) which has campaigned to increase access to antiretroviral medication and to coax the government into adopting a national treatment plan (TAC, 2002a), recently challenged the government's policy in court and won a decision in favour of pregnant HIV positive women on 14 December 2001 (TAC, 2001). As a result, the government was ordered to provide Nevirapine (an antiretroviral) to these women, to reduce mother to child transmission of HIV. Following the TAC's court victory, the government appealed this decision, withholding widespread access to Nevirapine. On 11 March 2002 the TAC won yet another court case forcing the state to supply Nevirapine at public health facilities and granting doctors the right to prescribe it, while awaiting the

outcome of the appeal (TAC, 2002b). At present the state and the TAC are still engaged in the appeal process. It is clear that the state has been reluctant to provide treatment for HIV positive individuals. Therefore except for those who are able to obtain antiretroviral treatments through some other means, most South Africans have been unable to gain access to these treatments.

While there appears to be common elements to the experiences of people living with terminal diseases, there are several features of HIV/AIDS that distinguish it from other diseases.

Individuals living with HIV may face many more uncertainties and losses (Mead & Willemsen, 1995). They may be confronted with difficult questions, such as when and how they became infected and how long they will remain asymptomatic (Evian, 1993).

Furthermore, they are likely to have to come to terms with losses, such as the loss of their health (and body image as they become thinner, develop skin markings due to conditions such as Kaposi's sarcoma and lose control of body functions if they develop diarrhoea), relationships, sex, future, job etc. (Sherr, 1995). Since most people infected with HIV tend to be young, it may be especially difficult for them to accept these losses (Mead, 1995).

In addition to coming to terms with uncertainties and losses and negotiating grief (Sherr, 1995), people living with HIV do so within a broader social context that stigmatises them.

AIDS appears to carry with it the combined burdens of coming to terms with a life-threatening illness and coming to terms with minority group discrimination (Tross, 1989).

The stigma associated with HIV infection may threaten both the physical and psychological wellbeing of infected individuals (Herek & Capitanio, 1993). Others often fear the possibility of infection and may thus enforce many social changes on the person living with HIV (Tross, 1989). Negotiating social stigma and other's fears may be difficult.

In a study investigating the pervasiveness of stigma associated with AIDS in the 48 contiguous states of the United States of America, Herek and Capitanio (1993) found that most of their respondents expressed at least some degree of stigma. Using telephone interviews, they collected data from two samples, a randomly selected adult English-speaking sample (n = 538) and a sample of English-speaking African-American adults (n = 607). Many respondents had a poor understanding of how HIV could be transmitted and believed that HIV could be transmitted through various forms of casual contact including kissing an infected person on the cheek (18,5% of the general sample and 23,3% of the African-American sample), sharing drinking glasses with infected individuals (47,8% of the general sample and 54,6% of the African-American sample) and using public toilets (34,3% of the general sample and 48,2% of the African-American sample).

More concerning than their poor understanding of transmission was that respondents harboured many negative feelings towards people living with AIDS. Many reported being afraid of people living with AIDS (35,7% of the general sample and 35,1% of the African-American sample). Slightly lower levels of disgust (27,7% of the general sample and 23% of the African-American sample) and anger (27,1% of the general sample and 21,1% of the African-American sample) at people living with AIDS were also reported. Respondents also exhibited coercive attitudes towards infected individuals. Many felt that infected individuals should be separated from the general public (35,7% of the general sample and 40,1% of the African-American sample). There were also many who felt that infected individuals' status should be made public so that they could be avoided (30,2% of the general sample and 40% of the African-American sample). Many respondents also expressed intentions to avoid others who had been infected. Examples of this include that 47,1% of the general sample and 55,6%

of the African-American sample stated that they would avoid shopping at a local grocery store if the owner had AIDS. Furthermore, 12,5% of the general sample and 14,3% of the African-American sample asserted that they would avoid a close friend with AIDS. It would appear that stigma and animosity towards people living with AIDS was (and probably still is) a major problem in the United States (Herek & Capitanio, 1993).

In another study related to stigma, Fife and Wright (2000) compared the effects of the stigma associated with HIV/AIDS and cancer "...on self-esteem, body image, and personal control" (p.50). Their sample consisted of 130 people with HIV/AIDS and 76 people with cancer from a city in the Midwestern region of the United States, who were selected using a convenience sampling technique. Several measures were administered to participants. The HIV/AIDS sample had higher means on every measure, suggesting that they experienced higher levels of social rejection, financial insecurity, internalised shame and social isolation. This ultimately suggests that they experienced higher levels of stigma than the cancer sample. The higher levels of stigma associated with HIV/AIDS may cut many individuals off from much needed social support, increasing their susceptibility to psychopathology.

People infected with HIV/AIDS are vulnerable to various forms of psychopathology (Tross, 1989). Els *et al.* (1999) found that 58% of HIV/AIDS patients attending hospitals around Bloemfontein met the diagnostic criteria for a psychiatric disorder. These included major depressive disorder, panic disorder, social phobia, specific phobia, generalised anxiety disorder and, less commonly, dysthymia, bipolar disorder, agoraphobia, obsessive compulsive disorder, post traumatic stress disorder and substance abuse. Other studies have also found high levels of psychopathology among AIDS patients. The American Psychiatric Association (A.P.A.) work group on HIV/AIDS report that the most common psychiatric

disorder associated with HIV (presumably in the USA) is depression, which is experienced by 4% to 14% of AIDS patients (cited in Ferrando & Wapenyi, 2002). Furthermore, 50% of AIDS patients seeking psychiatric treatment have a diagnosis of depression. Lyketsos, Hulton and Fishman report that 4% to 22% of men and 2% to 18% of women with HIV experience depression during the course of their infection (cited in Ferrando & Wapenyi, 2002). Wagner, Rabkin and Rabkin found that up to 11% of HIV patients had anxiety symptoms (cited in Ferrando & Wapenyi, 2002). It thus appears that HIV/AIDS may have a significant psychological impact on infected individuals.

HIV is thus a difficult disease to live with. Infected individuals may be plagued by various opportunistic infections. They are also prone to developing malignancies. The treatments which are available are expensive, largely unavailable to South Africans and offer no hope of cure. Furthermore, it appears that HIV infected individuals may be confronted by stigma and prejudice. These factors may make HIV more difficult to live with than cancer. However, as has been noted, much of the research that has been cited is based on European and North American populations.

While both cancer and HIV/AIDS dramatically affect the lives of people living with these conditions, they also have a dramatic impact on the lives of those who are caring for them. Often the task of caring for someone with a terminal disease falls on the family. Thus, the family is often deeply and intimately affected by these illnesses.

2.3 The impact of cancer and HIV/AIDS on families

Cancer and HIV/AIDS are often viewed by counsellors and researchers as diseases affecting individuals (Bor, Miller & Goldman, 1993; Coyle, Localzo & Bailey, 1989; Hughes, 1987;

Marcus, 1999; Portenoy & Foley, 1989; Rait & Lederburg, 1989; Schlebusch, 1999; Williams & Stafford, 1991). However, for every individual with cancer or HIV/AIDS, there is also a group consisting of family and friends with whom they are in a relationship. Because these patients are often cared for at home, their family, and sometimes their friends, are often responsible for a great deal of the patient's care and may thus be intimately involved in and affected by the patient's illness.

While families are often ignored in research, a further problem is that the families that have been studied are sometimes members of very specific population groups. A decade ago Williams and Stafford (1991) noted that most research into the impact of HIV/AIDS on families focused on the families or partners of gay males or of substance abusers. Thus, few studies addressed the impact on families where the patient was a non-drug abusing heterosexual. In recent years this has changed, but many texts and studies still refer to a homosexual and substance abusing HIV/AIDS population. This is unfortunate, since the majority of infected individuals in Sub-Saharan Africa are heterosexual. Consequently much work still needs to be done to study the impact that HIV/AIDS has had on families in this region.

There are many common aspects to the ways that HIV/AIDS and cancer affect families. Both cancer and HIV/AIDS place a strain on families regarding caring, finances, emotions, decision-making and family organisation. However, there are also several unique ways that they affect families due to factors particular to the diseases themselves. Due to the nature and social significance of HIV/AIDS, it may have a more severe impact on families.

2.3.1 Increased burdens related to caring for the ill family member

Caring for a chronically ill family member can place many demands on a family. Some authors have noted that it may be physically difficult work (Jacobsen & Holland, 1989; Lesko, 1989; Marcus, 1999; Rait & Lederberg, 1989). Following procedures such as surgery for cancer, many patients recuperate at home (Jacobsen & Holland, 1989). This can involve considerable physical care as family members assist with bathing, changing dressings and other nursing duties. In an exploratory qualitative investigation of poor people's perceptions of death and dying in several communities around Pietermaritzburg, Marcus (1999) ran 15 focus groups with adults, mostly women, over 35 years of age. She found many of the participants in her study felt that caring for a family member with HIV/AIDS was physically difficult work that could impact negatively on the health of caregivers. It is noteworthy that it was usually female family members that bore the burden of care related work (Marcus, 1999; Rait & Lederburg, 1989).

In addition to the physical burden, it is also emotionally draining caring for ill family members (Marcus, 1999; Rait & Lederburg, 1989). Rait and Lederburg (1989) note that while family members are intimately affected by the illness, they need to be able to contain their emotions in order to support the patient. Family members of cancer patients may attempt to appear brave so as not to burden the patient or appear selfishly absorbed in their own problems instead of placing the patient's welfare first (Hughes, 1987). They may also avoid pleasurable activities so as not to appear frivolous or callous. Family members caring for a HIV positive family member may behave similarly. Thus, while trying to support the ill family member, other family members may sacrifice their own emotional wellbeing and cut themselves off from social support which has been noted to act as a buffer to stress (McCubbin *et al.*, 1980; McCubbin & Patterson, 1983, Patterson, 1989).

The many costs involved in caring for an ill family member may place a financial burden on families (Bor, Miller & Goldman, 1993; Marcus, 1999; Rait & Lederburg, 1989; Schlebusch, 1999). Bor, Miller and Goldman (1993), in their review of literature related to HIV/AIDS and its impact on the family during the 80's, observed that chronic terminal illnesses generally increased the financial burden on families. This results both from the direct costs of treatment and the loss of productivity in the family. In her study, Marcus (1999) found that ill family members were often forced to stop working due to their failing health. Furthermore, other family members often also needed to give up working in order to care for the ill family member. This also occurs in families caring for a family member with cancer (Rait & Lederberg, 1989; Schlebusch, 1999). Chronic illness can thus be financially debilitating.

Families may also help an ill family member to gather and consider information and make decisions. A lot of information often needs to be considered and decisions made in response to conditions such as cancer and HIV/AIDS. Families often help the ill family member by assisting and sharing the responsibility of decision making (Rait & Lederburg, 1989). This can be difficult for family members and increase the burden of stress on families.

As a response to the impact of cancer and HIV/AIDS, a family may experience changes to its structure as a response to changing needs and demands. Some needs have already been discussed and include the family's financial and caregiving needs. The family may need to adjust its organisation and some family members may need to take on new roles. Schlebusch (1999) notes that families caring for a family member with cancer frequently enlist adult children and also adolescent daughters to take on caregiving roles. In families that are caring for a family member with HIV/AIDS the grandparents often assume the caregiver role (Bor,

Miller & Goldman, 1993; Marcus, 1999). Marcus notes that in families caring for a family member with HIV/AIDS the financial and caregiving burden is often borne by the elderly female members of families. These illnesses may thus significantly alter the structure of a family, typically increasing the burden on female family members.

2.3.2 Sexual and reproductive difficulties

Another stressor between married partners may be the possibility that these illnesses, or their treatment, can impact on the sexual and reproductive functioning of the patient. This in turn affects their partner as well. As has been discussed, sexual problems may arise from many cancers either from the disease, its treatment or as a psychological consequence. According to Schlebusch (1999), another difficulty that can arise among cancer patients is that the healthy partner may not wish to initiate sex because of their concerns for their partner's health.

Cancer can thus have sexual and/or reproductive consequences for families.

Marital couples with an HIV positive member may also experience sexual and reproductive difficulties. Marcus (1999) reported that many people in her focus groups had difficulties in these areas. As many of those infected with HIV are young, it may also be difficult for them to give up the possibility of having children. Many couples feel such a strong desire to have a child that they resort to unsafe sexual practices, regardless of the infection risk to both themselves and the child thus conceived (Bor, Miller & Goldman, 1993). There is a high risk that the baby could get infected with HIV. McIntyre and Grey (2000) report that some South African studies have found a mother to child transmission rate exceeding 35% in the absence of any type of intervention and with breastfeeding being practiced. Despite this, the sexual and reproductive functioning of a couple may be very important to them and it may thus be difficult to sacrifice.

2.3.3 The uniqueness of HIV/AIDS

Despite the similarities discussed above regarding the impact that cancer and HIV/AIDS can have on families, each illness also has a unique impact. In particular, HIV/AIDS has several distinctive features which increase the burden on families. Families caring for an infected family member are typically confronted by a long and uncertain period of illness (Bor, Miller & Goldman, 1993; Sherr, 1995). While this may allow them a greater period of time to come to terms with the illness, it also extends the period of disruption in families. Periods during which the ill family member is affected by an opportunistic infection may serve to retraumatise the family. The increased illness period may thus be difficult for families.

Families are also confronted by stigma (Atkins & Amenta, 1991; Bor, Miller & Goldman, 1993; Marcus, 1999). This may in turn lead to secrecy and isolation. In Marcus' (1999) study many participants preferred not to refer to HIV by name, but instead used euphemistic terms and illnesses such as TB or pneumonia to refer to it. Participants related the shame and embarrassment surrounding the disease to its association with sex, and particularly unregulated sex. They often preferred to keep a diagnosis secret due to shame and the fear of possible stigma. The fear of stigma may also cause families to isolate themselves, thereby reducing their access to social support (Bor, Miller & Goldman 1993). Others may in turn also distance themselves from the family. While they do not always do so overtly, they may do so through more subtle means such as not inviting children to parties. Stigma and the ensuing social isolation appear to be commonly experienced by families caring for a family member with HIV/AIDS.

HIV/AIDS also affects families in other ways. As has been noted, many of those affected by HIV are young. The disease may thus have a dramatic effect on the family's lifecycle. Unlike cancer, HIV is infectious, therefore families may be confronted with fears surrounding contagion and infection (Atkins & Amenta, 1991). These families may also be more likely to experience multiple deaths (Marcus, 1999). For these, and the reasons mentioned in the preceding paragraphs, families affected by HIV/AIDS may be confronted with more difficulties in their adjustment, than families affected by cancer. This may place these families at a greater risk for psychopathology (Bor, Miller & Goldman, 1993).

2.3.4 Psychopathology related to caring for a family member with cancer or HIV/AIDS

Family members are deeply affected by the illness of their family member. In a study comparing the psychological symptoms of bereaved parents of adult children who died of cancer to those whose adult children died of AIDS, Normile (1990) administered the Symptom Check List 90-R (SCL-90R) to 58 parents. Parents who were bereaved by AIDS were found to have significantly higher mean scores than parents bereaved by cancer on the somatisation, depression, anxiety and obsessive compulsive dimensions. Furthermore, they also had higher scores on the Global Severity Index (GSI). She suggests that this may place them at a high risk for developing complicated grief and/or physical illnesses. The greater severity of symptoms experienced by grieving parents of adults who died of AIDS may also suggest that they experience more difficulties and symptoms caring for their children while they were alive. The next section will examine several theories which have been used to study how families experience stress.

2.4 Theories of family stress

A number of theoretical models have been used to explore the relationship between physical illness and family functioning (Baker & Patterson, 1989). Many of these, such as Olson's Circumplex Model (Olson, Russell & Sprenkle, 1983) and the Beavers Systems Model (Beavers, 1989; Beavers & Voeller, 1983), are theoretical models of family structure. They have been used to explore how this relates to health outcomes (Baker & Patterson, 1989). Another line of inquiry has explored how families are agents within the illness process itself (Baker & Patterson, 1989). The Family Adjustment and Adaptation Response model (FAAR) (McCubbin & Patterson, 1983; Patterson, 1989) is a more comprehensive model that has been used to explore this line of inquiry. These models will be discussed below.

The Circumplex model was developed through an examination of clinical and empirical literature related to family functioning (Baker & Patterson, 1989; Beavers & Voeller, 1983; Olson, Russell & Sprenkle, 1983). The model consists of two dimensions, namely adaptability and cohesion. These dimensions are orthogonal, curvilinear continuums. Ideal family functioning is situated at the centre of each of these dimensions and pathology at the extremes. Thus, families with moderate levels of adaptability and cohesion are considered to be healthier and hence better resourced when confronted with stressor events.

The Beaver's family systems model is similar to the Circumplex model. It integrates two dimensions, namely family competence and family style (Baker & Patterson, 1989; Beavers, 1989; Beavers & Voeller, 1983). Family competence is a linear variable reflecting the family's ability to effectively negotiate stressful situations. It ranges from severely dysfunctional to optimal. The more adaptive and competent a family is, the more able it is to deal with stressful events. This requires both structure and the ability to adapt the family's

structure according to demands. Family style, on the other hand, is a curvilinear variable with two poles: centripetal (where relationship satisfaction comes from within the family) and centrifugal (where relationship satisfaction comes from outside of the family and hence there is a tendency within the family system to push family members out). Competent families are able to adapt and change their style to meet the needs of individual family members. Healthy and hence better resourced families are able to adapt and change and do not adhere rigidly to either a centripetal or centrifugal style.

Both the Circumplex and Beavers models have been used to explore questions such as the relationship between the family's response to an illness and the family's structure (Baker & Patterson, 1989). While this is a useful line of inquiry, it neglects many important factors that impact on the family and contribute to the family's response to an illness. In this regard, the FAAR model is useful as it integrates factors such as families' abilities and the demands faced by families in order to describe the impact that stressful events have on them.

The FAAR model evolved over the course of three decades of family stress theory building (McCubbin & Patterson, 1983; Paterson, 1989). It expands on Hill's (1948 & 1958, as cited in Patterson, 1989) family crisis model which was developed from a study examining families' responses to war separation and reunion. The model, referred to as the 'ABC-X' model, postulates that a stressor event (A) interacts with a family's resources (B) and perceptions (C) in order to produce a crisis (X). This model forms the foundation from which the FAAR model was developed.

In a longitudinal study utilising the ABC-X framework to study families with a husband/father who was either missing in action or a prisoner of war in Vietnam, McCubbin,

Dahl and Hunter (1976, cited in Patterson, 1989) found that factors other than Hill's A, B, C and X were necessary to explain a family's adaptation over time. Consequently McCubbin and Patterson developed the double ABC-X model. This introduced post-crisis variables in order to explain how families recover from crises and adapt. Furthermore, they incorporated this into a process model (which they called FAAR). This model explains the processes by which families achieve pre-crisis adjustment and post-crisis adaptation.

The FAAR model focuses on families' attempts to deal with demands, in accordance with their capabilities, mediated by their meanings, in order to achieve a balance in family functioning (Patterson, 1989). Patterson (1989) defines demands (factor A) as "...a stimulus or condition that produces or calls for change in the family system" (p.100). Demands produce a state of tension in the family, requiring them to direct their abilities toward reducing the tension. When the family is unable to meet its demands, a state of stress arises.

There are two sources of demands, namely stressors and strains. Stressors are discreet life events which may produce a change in the family system (Patterson, 1989). Stressors may be normative events in the family's, or in individual family members' development, such as children passing through adolescence or marrying. Stressors may also be non-normative events such as the death of a family member due to an illness. The defining characteristic of stressors is that they are relatively discreet events. Strains differ from stressors in that they are not discreet events (McCubbin, 1983; Patterson, 1989). They tend to be more insidious in their development. They may be associated with the incomplete resolution of previous stressors or with role relationships where there is a discrepancy between one family member's expectations of another's performance and the other's actual performance. When

stressors emerge, strains present as pre-existing conditions, which may be exacerbated by the stressor. Both place demands on families' capabilities.

Families deal with demands in accordance with their capabilities (factor B) (McCubbin, 1983; Patterson, 1989). These include resources and coping behaviours. Resources are comprised of the competencies and abilities of individual family members, the family as a whole and the community. Examples of individual resources are self-esteem and intelligence. Family abilities are addressed by models such as Olson's Circumplex model and the Beavers Systems model, which have already been described. Community resources include social support and affiliations to religious and other organisations. Coping behaviours are behaviours practiced by families in order to maintain a homeostatic balance between resources and demands. The more resources and capabilities families possess, the more able they are to cope with demands.

Factor C of Hill's model (1949, in Patterson, 1989) addressed the way that the family defined a stressor. In the double ABC-X model this was expanded to include 'situational meanings' and global meanings (McCubbin, 1983; Patterson, 1989). Situational meanings arise as a result of prior experiences. Sometimes however, due to the lack of prior experience, a sense of ambiguity arises which may exacerbate demands. Global meanings are more stable and continuous than situational meanings and could be described as core beliefs or even as a family schema. These include assumptions regarding the relationships between family members as well as between the family and other systems. Demands, capabilities and meanings interact with each other as the family deals with stress.

There are two phases to the FAAR model, namely adjustment and adaptation (McCubbin, 1983; Patterson, 1989). These are separated by a crisis period during which the family's homeostatic balance is upset. During the pre-crisis or adjustment phase, there is a state of relative homeostasis within the family. Families in this stage try to make adjustments to their interaction patterns with minimal changes to their existing structure or behaviour patterns. They resist major changes to the family system and are able to meet their demands, with their existing capabilities. At this point the family is still operating within the first 'ABC' of the FAAR model. However, when a family's capabilities are no longer adequate to meet their demands, such as when they are overwhelmed by a stressor, then they are no longer in a state of equilibrium and are plunged into a state of crisis (factor X).

Families experience crisis as uncomfortable and feel vulnerable in this state (McCubbin, 1983; Patterson, 1989). They thus try to adapt in order to restore equilibrium to the system. This takes the family into the next 'ABC' of the FAAR model. The 'ABC' factors of the adaptation phase are directed at bringing about a change to the family system. Adaptation can entail changing the family's meanings in order to account for their circumstances. It can also entail reducing the pile-up of demands or the development or acquisition of new resources. Finally it may also involve developing new coping strategies for dealing with demands. Family adaptation differs from family adjustment, in that the family's existing capabilities are no longer sufficient to deal with demands and a second order change is thus necessary. This entails a change to the family system itself.

The psychological and physical wellbeing of family members is vulnerable to the level of adjustment and adaptation in the family system (Patterson, 1989). Both are related to emotions and cognitions which may be influenced by the family system. Therefore there is an

interaction between the health of the family system and the health of individual family members; while the family may be deeply affected by the illness of a family member, the wellbeing of individual family members can also be related to the health of the overall family system.

The FAAR model thus considers many more factors than the Olson and Beavers models. While these are models of family functioning, the FAAR model explores how several factors interact in the family stress process. It is a more comprehensive model that views the family as an agent within the stress process itself.

With regards to stress, it appears that while both cancer and HIV/AIDS significantly affect families, a review of the literature suggests that caring for a family member with HIV/AIDS may have a more severe impact on families, than caring for a family member with cancer. However, much of the research on HIV/AIDS is based on Western European or North American samples which differ from the South African HIV positive population (Joubert, 1991). The local population may also be exposed to different stressors. It is thus important to develop local research on the impact of HIV/AIDS on families.

While some family systems models such as the Olson's Circumplex Model (Olson, Russell & Sprenkle, 1983) and Beavers Systems Model (Beavers, 1989; Beavers & Voeller, 1983) have been used to study the relationship between health outcomes research and family structure, another, more comprehensive line of inquiry has examined how the family is an active agent in the illness process (Baker & Patterson, 1989). The FAAR model (McCubbin & Patterson, 1983; Patterson, 1989) can be used to explore this line of inquiry.

As little research has been done in South Africa in this area, an exploratory qualitative methodology capable of discovering new data has been adopted. The following section describes this methodology.

3 Method

3.1 Design

This study employs an exploratory comparative case-study based hermeneutic-phenomenological methodology. It explores the stress experienced by families caring for a family member with HIV/AIDS, comparing this to the experience of families caring for a family member with cancer. As these illnesses both affect a similar amount of South Africans, and both are chronic conditions, it is felt that a comparative study would highlight the unique impact that factors, such as stigma, have on families caring for a family member with HIV/AIDS.

Hill (1949, as cited in McCubbin *et al.*, 1980) defines a family stressor as a life event of sufficient magnitude to change the family system. A pending death in the family is such a life event. The resulting stress is not inherent in the stressor, but is a function of the family's unique response to it (Baker & Patterson, 1989; McCubbin *et al.*, 1980; McCubbin & Patterson, 1983). This response involves factors such as meaning and interpretation. A hermeneutic-phenomenological methodology is well suited to investigating these phenomena.

Hermeneutics has been influenced by phenomenology (Palmer, 1969). Phenomenology rejects empiricism as a methodology in the human sciences, asserting that it cannot explore human existence (Heidegger, 1982; Kruger, 1979). It is essentially concerned with the study

of people in their world (Braine, 1984). Heidegger (1982) focused his attention on being (or existence, referred to as 'Dasein'), distinguishing it from beings (or objects, referred to as 'Sein'). Being is bound to beings but cannot be reduced to beings; it exists at a level beyond beings and cannot be studied by observation as beings can. However, being is inseparable from the world and is always bound up with an individually formed worldview shaped by environmental factors such as class and culture. The individual's connection to the world is referred to as their 'lebenswelt' or 'life-world'.

The phenomenological method is inductive, demanding that phenomena be approached with as few presuppositions as possible (Braine, 1984; Kruger, 1979). The aim is to arrive at a subjective understanding of being within the context of a particular lebenswelt. The result of this process is an in-depth description of the phenomena showing its essential characteristics (Braine, 1984). This allows access to those aspects which are uniquely human.

Phenomenology has made a valuable contribution to the human sciences by emphasising the importance of an in-depth understanding of individuals within the context of their environment. While this process is recognised as being subjective, no room is left for the acknowledgement of the role that preconceptions play in the interpretation. Hermeneutics, while still aiming to gain an in-depth understanding of the phenomena, emphasises the role of preconceptions and theory in interpretation.

Hermeneutics primarily addresses textual interpretation (Palmer, 1969; Ricouer, 1981; Welman, 1995). It originated in the field of biblical exegesis and became established as a formal method of enquiry in the social sciences through the work of authors such as Dilthey (Palmer, 1969; Welman, 1995). Hermeneutics is reflexive and emphasises the lack of interpretative neutrality in the interpretation process (Palmer, 1969; Ricouer, 1981; Welman,

1995). The preconceptions held by researchers are not viewed as prejudice, but rather as an “anticipatory structure of understanding” (Ricouer, 1981, p. 58). Interpretation involves a dialectical relationship between the interpreter and the text referred to as the hermeneutic circle or arc (Palmer, 1969; Ricouer, 1981; Welman, 1995). The interpreter enters into a relationship with the text with a set of preconceptions. However, in accordance with the hermeneutic circle; there is a continual return to the text as the interpreter tests out their interpretations and theories and refines and alters their understanding. Thus, while the interpreter enters into the interpretation process with a set of preconceptions and attempts to understand the text in the context of previous work, their interpretation must be grounded in and refined by the text.

In this study data for interpretation were collected through a series of case studies. Case studies have a long history in psychology (Huysamen, 1994). The work of Freud and Piaget is largely based on data collected from case studies. Case studies are directed at understanding the uniqueness and idiosyncrasies of a particular case in all of its complexity. This allows an in-depth examination of a particular case. Case studies are thus often employed, as in this case, in exploratory research.

Exploratory research is useful in exploring a well-researched issue in a local context (Mitchell & Peil, 1982). As with this project, it is usually conducted on a small scale and is often seen as leading the way to more comprehensive work. This research relies on case studies of four families who were interviewed regarding their experience of caring for a family member with either HIV/AIDS or cancer. An exploratory approach was necessary in order to study the impact that HIV/AIDS has on South African families.

By comparing the experiences of families caring for a family member with HIV/AIDS to those caring for a family member with cancer, this project is comparative. Implicitly this is a component of all social science research as studies are generally contextualised in relation to other research (Mitchell & Peil, 1982). As both cancer and HIV/AIDS affect the lives of many South Africans, it is felt that a comparative methodology highlights some of the unique features of caring for a family member with HIV/AIDS.

An alternative to the above-mentioned method may have been to investigate the phenomenon with a more quantitative methodology. Many quality of life questionnaires have been developed which could have been used to investigate the impact of stress on the quality of life of individual participants. There are however, several shortcomings associated with this design. Questionnaires such as the Medical Outcomes Study (MOS) (Revicki, Chan & Gevirtz, 1998), the Medical Outcomes Study HIV health survey (MOS-HIV) (Wu, Revicki, Jacobson & Malitz, 1997), the HIV/AIDS-targeted Quality of Life instrument (HAT-QoL) (Holmes & Shea, 1997; 1998), the Functional Assessment of Human Immunodeficiency Virus Infection quality of life instrument (FAHI) (Cella, McCain, Peterman, Mo & Wolen, 1996), the HIV Overview of Problems Evaluation System (HOPES) (DeBoer, Spranger, Aaronson, Lange & Van Dam, 1996) and Cleary *et al.*'s (1993) questionnaire, were developed for the assessment of individuals with HIV/AIDS, and not for family members caring for them. They were also developed and normed for North American and European populations which are predominantly male and homosexual. Extensive work still needs to be done in order to adapt these devices for other populations (Sullivan, 1994), such as South Africa. Devices such as these would also not be useful for an exploratory study such as this, as the research would be deductive rather than inductive and would thus not allow for an unfolding of the participant's own meanings. In this regard a hermeneutic-phenomenological

methodology is far more useful. The selection of the participants was a crucial component of this exploratory and comparative research design.

3.2 Participants

The exploratory design explores the experiences of a small number of participant families in depth. In order to ensure that these few participants would be able to provide useful data, they were purposively selected. Purposive samples allow for the selection of a few cases that are considered to be typical or occasionally outstanding examples of the variables being studied (Huysamen, 1994; Mitchell & Peil, 1982). While such a methodology is useful in exploratory research, it is coupled with the drawback that it is impossible to assess how representative the sample is of the general population. Thus, in-depth exploration of a few cases comes at the expense of losing generalisability.

Four families were selected for this project. As this design was comparative, it was necessary that participant families matched each other as closely as possible on variables such as class and culture. Due to financial constraints it was also important that the families could speak English in order to avoid the expense of translators. Furthermore, a review of the literature revealed that several authors were concerned with the impact of chronic terminal illnesses on families based on the role of the ill family member (for example Hughes, 1987; Schlebusch, 1999; Sherr, 1995; Worden, 1991). Of particular concern were families where the ill family member was the primary breadwinner, primary caregiver or a child. The aim was thus to obtain participants who matched each other in terms of class and culture, spoke English, and to match the cancer and AIDS participant families in terms of the role of the ill family member.

It proved to be difficult sampling participants. This may be due to the difficult and personal nature of the experience being studied. Several NGOs in Pietermaritzburg and Durban were approached. The research question, my status as a student, and the purpose of the research as an academic requirement were discussed with these organisations and assurances were made regarding the confidentiality of participants. Arrangements regarding counselling were also discussed. These organisations all had their own counselling staff that were supporting families. The research interviews were viewed as a therapeutic encounter and the participating NGO's generally requested feedback regarding the wellbeing of participants (a matter which was discussed and consented to by the families concerned). Eventually, after interviewing several different families, four families who matched each other according to the above criteria were sampled.

All of the families selected were from the Indian community, had a Hindu background, had members who mostly performed manual labour and had a monthly family income lower than R4000. After the NGO's asked the families' permission, the families were approached, and the same matters regarding the status of myself and the research were discussed with them. Confidentiality was also discussed and each family member signed consent forms (see Appendices A and B), consenting both to participation and to the taping and transcription of the interviews. The forms were read to participants who could not read before they signed them. Consent and confidentiality was also discussed at the beginning of interviews (see Appendix C for a copy of the interview guide). All participants in this project consented to their participation. Except for the Govender family, who insisted that their identities not be disguised, all identifying data and names of the participant families have been changed.

The four participant families selected for this project included a family where the primary breadwinner had cancer, a family where the primary breadwinner had AIDS, a family where the primary caregiver had cancer and a family where the primary caregiver had AIDS. Participant families with ill children could not be found. The two families with a family member with HIV/AIDS were thus matched with two families with a family member with cancer.

3.3 Equipment and Measures

For this study a data collection method was required that could access the unique experiences of participants. Semi-structured interviews were utilised with an interview guide loosely based on McCubbin's FAAR model (McCubbin & Patterson, 1983; Patterson, 1989). These interviews were taped and then transcribed.

Semi-structured interviews offered a number of advantages. An interview permits data to be collected from the primary source, rather than from secondary sources such as documents (Labovitz & Hagedorn, 1981), allowing more intimate and interactive access to participant's experiences. As several of the participants in this study were illiterate, interviewing proved useful, as this was not a hindrance. Furthermore, semi-structured interviews are a versatile instrument. The phrasing of questions and terminology could be altered according to the participant's background (Huysamen, 1994). Questions that participants struggled to understand could be explained if necessary. Responses could be probed, allowing interviewers to explore issues in depth (Huysamen, 1994; Labovitz & Hagedorn, 1981). Semi-structured interviewing gave more room to revealing emotions than more structured approaches, allowing increased access to participants' lebenswelt (Huysamen, 1994). Such an

understanding could not be gained utilising more rigid data collection techniques such as questionnaires (Kruger, 1979).

There are however, also a number of drawbacks associated with semi-structured interviewing. It is difficult to assess whether participants are being honest, basing their responses on what they believe the researcher wants to hear or if they are voicing a general group opinion rather than their own (Labovitz & Hagedorn, 1981). Questions may also tap opinions, attitudes, or perceived behaviour rather than actual behaviour. Because questions are unstructured there is also little comparability in the wording of questions from one interview to another. Interviewing the whole family together appears to have counteracted some of these difficulties. It was noted that participant family members would occasionally disagree with one another or rectify each other regarding behaviour and experiences. For example one son initially suggested that he was upset by his mother's cancer, but this did not affect him much and he was coping well. His mother disagreed, saying that he had difficulties at school. These 'rectifications' appeared to introduce information on behaviour that some individuals had not noticed or were unaware of. Thus, the family, interviewed together created an interesting source of information in that each individual family member was both a participant and an observer of others in the group. While there were some problems associated with interviewing it was felt that a more structured methodology would have been unable to access the subjective information explored in this project.

Participants were interviewed using the interview guide in Appendix C. The aim was to engage families in a discussion about their experiences (i.e. to focus on the section of the guide titled "discussion of the illness"). Compiling a genogram and discussing the structure of the families served both as a source of information regarding the structure of families and

as an opportunity to establish rapport and ease families into the interview. The rest of the guide was designed to probe areas where families may have experienced stress or which may have exacerbated or mediated stress within families. Ultimately however, families were encouraged to tell their story.

This semi-structured interviewing technique accorded well with Hermeneutics. Researchers always approach the phenomena to be studied with a set of preconceptions. These are reflected in the interview guide (Appendix C). Ultimately however, the aim of this interview technique was to access participants' personal experiences rather than to merely obtain answers to questions. The areas addressed in the interview guide served as probes which were in turn examined on the basis of their relevance to participant's experiences in accordance with the hermeneutic circle.

3.4 Procedure

It proved difficult to gather research participants for this study. It took almost 20 months to find enough participants. Initially two families were interviewed and used as pilot studies. The DeVilliers' were an Afrikaans 'white' family contacted through an NGO in Pretoria. Both parents had been infected with HIV for approximately 12 years. The Williams' were a 'coloured' family contacted through an NGO in Pietermaritzburg. The father had AIDS. These interviews yielded good results and the data collection technique was not altered.

The sampled families were interviewed in the family home. Most families were interviewed only once, with the exception of the Govender family who were interviewed twice. The first interview ended early when half the family left for a course at their church. It was found that because the families were selected due to the advanced terminal nature of their illness, they

had already experienced an 'illness journey'; they had struggled with such factors as the disease, caring and treatment for a long period of time. Sufficient data could be gained from a single interview as the family could reflect on their illness journey and the stress that they had experienced and were currently experiencing.

Prior to being analysed, taped interviews were first listened to three times each in order to familiarise myself with the interviews. Following this, transcripts were analysed using Ritchie and Spencer's (1994) thematic analysis technique, 'Framework'. This process involves several stages. The first is 'familiarisation' and involves the researcher reading and rereading the transcripts, noting recurrent themes. Each transcript was read twice. The researcher then examines the notes made in the previous stage, attempting to identify issues, themes and concepts that can be used to study and reference the data in the 'identifying a thematic framework' stage. Data is then coded using the framework constructed in the 'indexing' stage. The framework and indexing was refined after three rereadings of the transcripts. The themes used to construct the framework in this study and a description of these themes refer to is presented in Appendix D. Data is then extracted from the text and arranged in charts with headings for each theme in the 'charting' stage. Finally, in the 'mapping and interpretation' stage, the researcher searches for key characteristics of the data and attempts to bring some unity to the material. Continual returns are made to the hermeneutic circle as interpretations are refined. The information gained from the charting stage is presented separately for each participant family in the 'results' section and the results of the 'mapping and interpretation' stage are presented in the 'discussion' section. Due to the volume of the transcribed material, this has not been included with this thesis. Transcriptions are however, available from the author on request.

It appeared that the families' experiences were affected by stressors as well as by mediating abilities, resources, meanings and experiences which affected the way that the families experienced the stressors. Each family's experiences of stressors and mediating factors will be discussed separately. Where direct quotes are made, 'E:' refers to quotes made by myself.

4.1 Families caring for a family member with cancer

4.1.1 A family where the breadwinner is the patient: The Mutara family

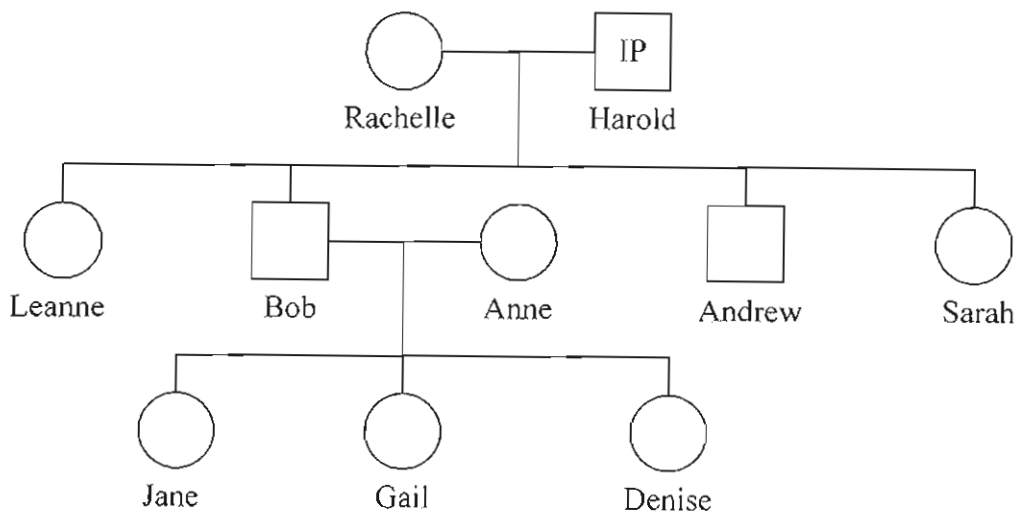


Figure 1: The Mutara family.

The Mutara family is an extended family with three generations of Mutaras living together. Harold is the charismatic and friendly family patriarch. Up until 18 months prior to the interview he had been in good health and was very active. A few months after his recent retirement, he developed several large protruding growths. In addition to this his health began to deteriorate. A doctor diagnosed him with lung cancer and he began to receive chemotherapy. Both he and the family believed that this treatment was progressing well.

4.1.1.1 Stressors

a FINANCIAL

The Mutara family struggled to meet several expenses, but felt that their situation was no different from that of most other families. At the time of the interview, they were six months in arrears with their payments on the children's school fees. Discussing this problem, Anne said, "...we are paying...but everyone, not only us...there are lots of parents out there struggling with school fees and things like that". Furthermore, while Harold's retirement resulted in a reduction in family income, this loss was not very significant. They did not struggle to pay medical expenses, as Harold was being treated at a provincial hospital and his pension was more than sufficient to pay for his expenses. The family had several sources of income: Rachelle earned money selling homemade goods, Bob and Andrew started a business and Leanne occasionally received financial help from her mother- and brother-in-law. They thus did not feel that their financial difficulties were overwhelming or any different from that experienced by many other families.

b CARING

Most of the caring in the family was done by Anne, who appeared to receive little acknowledgement for her work. Harold had many care-related needs. During the year preceding the interview, Harold's arthritis became debilitating, he was diagnosed with cancer and had a mild stroke. He had also received several courses of chemotherapy. Anne said: "We prefer giving (medication) to (Harold) than him taking it himself, because...he was getting very frustrated with his sickness and then he used to say he would rather take an overdose and things like that".

Anne performed most of the care-related tasks, receiving minimal assistance from other family members. It appears that Sarah sometimes helped to take Harold to the hospital, other family members assisted with several household chores and Harold occasionally heated up his own food. Anne was responsible for Harold's medication and wellbeing as well as for tasks such as feeding him and taking him to the hospital. While the family acknowledged that Anne performed all these tasks, they minimised her role. Harold described Anne as "very homely, very helpful too". Her work, which she describes as "difficult" was seen as part of her role as a housewife and was largely dismissed. Harold, on the other hand, was seen as an independent patriarch. He stated that he mostly cared for himself and was thus not difficult to care for. Anne also stated that Harold didn't like other people "tampering" with him, but "like(d) doing things for himself". When Harold occasionally heated up food for himself it was seen as evidence of his independence. Furthermore, Sarah appeared to exaggerate her role in caring, and appeared to receive more acknowledgement for her help from Harold. There thus appeared to be conflict in the family regarding caring. On the whole, Anne seemed to receive little recognition for her role in caring.

c ROLE CHANGES

Harold and Anne were the only family members who experienced significant role changes. Before becoming ill, Harold was very active. Becoming ill was difficult for him, as he could no longer do things for himself. Furthermore, Denise was angry with him because he stopped going on regular walks with her in order to buy her treats. She no longer saw him as a kindly grandfather. In order to care for Harold, Anne took on extra caring responsibilities. The changes to Harold's role as a grandfather, his transition to the sick role and Anne's increased workload, were difficult for them.

d ACCESSIBILITY OF MEDICATION AND TREATMENT

The Mutara family had no difficulties accessing medical treatment for Harold. After he was diagnosed he was referred to a provincial hospital for treatment. He had a good relationship with his oncologist and easily accessed treatment.

e UNCERTAINTY

There appeared to be uncertainty regarding Harold's health and treatment. Although Harold felt that his health was improving, he was not sure what was happening "internally". The family were also not sure about the future course of his treatment. While Anne felt that Harold could be getting better, she suspected that the oncologist could put him on another course of chemotherapy. On one occasion Harold asked the doctor how long he would live: "I asked him how long have I got to live, a month or 2 months or 5 years or 10 years or 6 months. He says no I will live a long time". The family and particularly Harold experienced the uncertainty about his prognosis and treatment as stressful.

f PSYCHOLOGICAL RESPONSES

The family appeared to be coping well with Harold's cancer. Anne reported that the family initially felt "depressed" but they had come to terms with the cancer. Harold on the other hand had difficulties adapting to his diagnosis.

Harold's cancer had a significant impact on him. In particular, chemotherapy was difficult for him. He lost a lot of weight during the course of his treatment, resulting in a dramatic change in his appearance. He was unhappy about his appearance and hoped to regain the weight as soon as possible. It was difficult for him watching other people receiving chemotherapy.

Discussing this, Harold said:

You know like it's upsetting man, like eh Thursday when I was having my chemo and then two patients were you know, bring up and that sort of has an effect on you. So I was

just looking away from that but you can hear them: ‘aag, aag’. You see that takes its effect on you. Other than that I don’t worry. The last time there was a young lady there with a little child ...and it was so sad that that worried me, so then I came home that night, ay, I was bringing up too.

It was difficult for Harold to come to terms with the effect that chemotherapy had on his body as well as the effect that sympathising with the other patients had on him.

Since being diagnosed, Harold became more irritable, especially with noise. He was often irritated with the children, alienating them from him. Discussing his increased irritability, Harold said it was “...mainly because of the illness you know...you can’t control your nerves”. Anne believed that his suicidality was also related to his frustration with cancer. It was difficult for Harold to cope with the impact that cancer had on him.

While Harold struggled to come to terms with the cancer and chemotherapy, the family managed to cope. They are mainly orientated to caring for Harold.

4.1.1.2 Mediating factors

a FAMILY ABILITIES

While Harold’s diagnosis was initially a shock for the family, they were a very cohesive family and this appeared to have helped them cope. They did not experience Harold’s cancer as an overwhelming stressor.

b SOCIAL SUPPORT

The Mutara family had an ambivalent experience of social support. Harold always had many friends, and said: “...friends are like busses; you miss one, you get another”. While he enjoyed company, it appeared that the Mutaras were inundated with guests visiting Harold. Discussing these visitors, Anne said:

Like we were starting to get visitors and many people were coming and you know they were making... it was getting awkward sometimes... But then we couldn't help that as well, because you see my father is a very well known person... and he was friendly.... and everyone, whoever heard up till now they still come. Last night we had visitors from Durban and they came around half past 8 and we were almost going to bed... And because they were in the area they came to see him... Sometimes we actually tell them, you know, if anyone comes now, tell them he is sleeping now, because he gets... tired of this.

While Harold generally enjoyed guests, he and the family were overwhelmed by the amount of visitors that they had.

Some social support was however, experienced as welcome. Sarah reported that a friend whose husband died of cancer helped the family a lot with information regarding caring for a person with cancer. A local NGO was also experienced as being supportive. Anne felt that "...they (were) always there", when they were needed. They also helped the family with information and caring. It appeared that the family welcomed support from people and organisations that were associated with cancer and death and dying. It possibly regarded these as more legitimate as they had experienced similar experiences.

c MEANING FACTORS

No meaning factors were apparent.

d STIGMA

The family did not appear to have experienced any stigma related to Harold's cancer.

4.1.1.3 Summary

The Mutara family appeared to be coping well. It was initially a shock for them to discover that Harold had cancer, but they managed to accept this and were mainly orientated towards caring for him. It appeared that Harold and Anne were the family members who had been most affected. Harold struggled to cope with his cancer, treatment and body image changes. He also became more irritable and suicidal. Anne experienced an increased burden in her

caring duties as a result of Harold’s illness and it appeared that much of this work was unrecognized. The family generally did not feel that their difficulties, such as their financial difficulties, were any different from that experienced by many other families. They experienced the local provincial hospital as very helpful and had no difficulties accessing treatment through them. While the family had had a lot of support from a local NGO, they were overwhelmed by the support that they received from others. It appeared that while the family was concerned about Harold, they were not overwhelmed by his illness.

4.1.2 A family where the caregiver is the patient: The Naran family

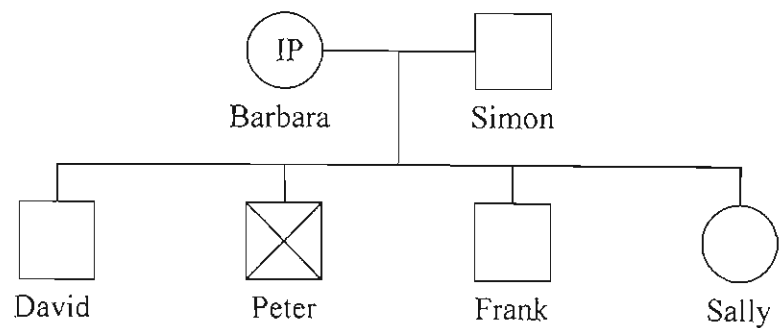


Figure 2: The Naran Family

The Naran family was struggling to cope. Having lost one of their sons, Peter, to cancer a decade before had been a difficult experience for them. They discussed this event more often than Barbara’s cancer. Simon and David regularly left the room when the interview became more emotionally charged. Simon and Barbara also frequently wept.

Barbara’s health had been deteriorating for more than three years. Initially she felt tired and struggled to do housework due to pain in her arm. Doctors unsuccessfully explored various diagnostic possibilities. Approximately six months prior to the interview Barbara discovered a tumour in her breast, which proved to be malignant. Following a radical mastectomy she

began chemotherapy. Later it was discovered that the cancer had metastasised to her bones. The way that the various themes were manifested in the Naran family are discussed below.

4.1.2.1 Stressors

a FINANCIAL

The Naran family appeared to be struggling financially. Peter's illness and death had depleted the family's savings. Furthermore, Simon struggled to cope with caring for both Barbara and the family as well as meeting his work commitments. Simon's company required all of its employees to reach a matric level of education by 2003. They thus implemented a mandatory adult education programme for employees. Simon said: "It's like I must go. I must go to school now for my age, but I still can't form to cope with the family and to do the studies". As a result Simon chose to drop out of the course, with the company's permission, in order to care for Barbara. Simon felt that this threatened his position at the company: "What will happen to me? That time will come, I am really out of a job and she is still going through the same thing..." However, while the Naran family had financial problems, they also had help.

Others were sympathetic to the Narans and offered them financial assistance. Simon's company offered Simon a loan, but because he could not afford to pay it back, they offered David part-time employment. The family also received financial help from other sources. Simon reported that the hospital helped them by placing Barbara on an oncology list even though they did not have adequate medical aid coverage. Furthermore, Rita reports that the pharmacy allowed them to buy R2000 worth medication on credit. Thus, while the family struggled financially, they also received a lot of help and understanding from others.

b CARING

Barbara's 3-year illness was difficult for her and her family. Each day Barbara needed a lot of medication. The chemotherapy affected her taste and her diet. She could no longer eat masala or chilli as these burnt the inside of her mouth. Furthermore, she could also no longer do housework. Barbara required a lot care.

Simon was responsible for most of the caring. He cooked, cleaned, cared for his wife and helped Sally with her homework. Other family members also occasionally helped with some chores. David helped take Barbara for blood tests. He did not however, take her for chemotherapy as this reminded him of Peter's cancer. While it was difficult helping his mother, it was also affirming for him. Discussing this, he said:

Ja, you see it's like, when we were growing up and our parents were taking care of us. So whatever we got to put back in is what we already took out. So it's not a problem for me. I mean, I still got a roof over my head and I am happy. As long as my family is happy, I am happy. I am not really; I am not feeling bad about it.

Helping his parents was very affirming for David. Frank on the other hand felt helpless.

Discussing his concern for his parents, he said, "I'm upset but I can't do anything". He could not take his mother to places and hence did not feel involved in her caring. It appeared that it was important for family members to feel that they were contributing to Barbara's care.

While it was important for Simon to care for his family, it conflicted with his role as provider. Simon's concern for his wife necessitated his departure from the company's adult education program (discussed in the previous section). This concern also affected his attention and concentration at work:

...At work for me, it breaks me down, very, very bad, because how do I keep my mind on my job...? Sometimes I phone, she's busy hanging clothes out and the phone only ringing one instant, so I, you know I get mind over matter, I just leave the receiver then I give her 10 to 2 minute chance, then I ring again, then I say "where you were?" "Oh, I was outside, I talk to the neighbour or something". Then I say, "Oh, its Ok, Ok." I get calm. You

know I wonder, these are the things that going to happen, you going to be where. Now who is here to... (check on) her...at home?

While Simon's concern for his wife affected his work, his company had been very understanding. As a result of the family's difficulties, Simon's managing director referred him to the company nurse. Through her he could arrange leave when needed to help Barbara. He also had permission to arrive late for work. Simon's company were very supportive.

c ROLE CHANGES

The family experienced several role changes adapting to Barbara's illness. Barbara used to perform all the caring tasks and Simon worked in order to provide for the family's financial needs. As discussed in the preceding sections, due to Barbara's illness, Simon assumed the providing and the caring functions within the family, with some help from David and Frank. These role changes were difficult and placed an increased burden on Simon. It was also not easy for Barbara to assume the sick role.

Barbara struggled to adapt to her new role as a sick person within the family. Discussing this she said, "...sometimes I just scream and I cry, looking at (Simon), because then I can't even help him. Because I was accustomed to doing things for them". Later, while discussing the chores that Simon did, she said apologetically, "...I never used to use Simon that way...".

Barbara was also upset that she could no longer help the children when they were ill:

I can't be there. So scary, I don't know what's going on in that room because they tell me straight, "Mommy you can't come inside here. Sister...told us that if we sick we must stay in the room". So he has to take that part too. Which is so unfair. I mean, what's wrong that he did that he has to...I feel that I am a burden to him. I'm really a burden to him.

Barbara felt very guilty that she can no longer perform her former role in the family and as a result experienced herself as a burden.

d ACCESSIBILITY OF MEDICATION AND TREATMENT

The Naran family easily accessed medical treatment. Doctors did initially struggle to diagnose her, but once diagnosed she was promptly placed on chemotherapy. She had no difficulties obtaining blood tests and medication for her chemotherapy induced insomnia. However, after Barbara nearly died after a drip was incorrectly inserted in hospital, the family were scared to contact doctors for Barbara. Discussing this fear, Simon said:

Doctor...always gets annoyed with us. He reckons, you must...he was, he on a 0800 number. He says if there is a problem at home, he says if any pain, any pain in her body, please phone. We don't do it and when we go see him he makes noise at us. He say, why? Then we say she had a pain here, now it's Ok. He reckons you must tell; let's investigate what the pain is about. So they can give her another kind of therapy or something mild or something, you know, more heavier drug or something like that for her.

It appeared that despite their fears, their oncologist was extremely accessible and concerned.

e UNCERTAINTY

Several factors caused uncertainty for the Narans. The family feared that there may be a genetic predisposition in the family for cancer. Discussing this, David asked "Is it genetic, because you know my brother, then my mother?" Furthermore, his paternal grandfather also died of cancer. Simon was concerned as well and said that he planned to test all the children for cancer following their doctor's recommendation. However, the biggest sources of uncertainty for the Naran family were Barbara's symptoms and prognosis. Discussing what cancer meant to her, Barbara said:

It's scary for me. Oh it's very scary; you don't know what's tomorrow.... Like it's so scary you don't know what's for you tomorrow. It's so scary; that even if I have a headache, (do)... I just have a side effect or it's a bug? ...I don't know whether I'm just picking up a flu but I know like it's a cancer pain...

The family experienced these sources of uncertainty as disconcerting.

Barbara's cancer was difficult for the family. They occasionally missed meals out of concern for Barbara. David also reported that they became more irritable with each other. To a large extent their current experience of cancer was inextricably bound up with Peter's cancer. This appeared to be especially true for David. Discussing his mother's cancer, he said:

I haven't really faced it properly to, to really realise. The only thing, every time I want to think about it, I think about my brother. That's why I don't really think about it so much. I just carry on; I wake up in the morning and say (its) a normal day for me. It's like a normal family day, there's no problems.

When he first heard of her cancer, Barbara said he withdrew from the family and refused to speak to anyone, prompting her to ask a counsellor from a local NGO to talk to him. At the time of the interview, David said he worked a lot:

...but the moment you start sitting down, even if you watching TV, the moment you sit down, you know it just pops in and you think about scenarios and what might happen and what could happen, what would happen, that you know.

It was clearly difficult for David to accept and cope with his mother's illness. He tried to distract himself from his concerns about his mother by working. At times he also used denial to cope.

Family members experienced various difficulties. David, Frank and Simon experienced various anxiety related symptoms. They felt anxious and struggled to sleep. Frank and Simon also experienced heart palpitations at times. Barbara stated that Frank also had academic problems. Talking about his experience of his mother's illness, Frank said "You keep pinching yourself; it's real or not?" It was also difficult for Barbara to accept.

Barbara's body image changed as a result of her cancer. Chemotherapy reportedly made her gain weight, forcing her to wear David's clothes. It was also difficult losing her hair: "I used to cry a lot about it, look at myself in the mirror, I used to scream". At the beginning of the

interview she covered her head with a scarf, which she sheepishly removed at Simon's insistence that she had nothing to be embarrassed about. She was upset that the pain in her arm prevented her from caring for her family. She also needed to avoid contact with her children when they were ill (see 'Role Changes'). It was difficult for Barbara to accept the changes in her body brought about by cancer and chemotherapy. She appeared to feel that due to her ill body, she had become a burden and was no longer attractive.

4.1.2.2 Mediating factors

a FAMILY ABILITIES

While the Naran family tried to support and care for each other, their past experiences and aspects of their coping style appeared to have been detrimental to their wellbeing. As noted, the Naran's current experience was bound up with their experience of Peter's cancer.

Approximately a sixth of the transcript referred to this event. Simon repeatedly referred to Barbara's cancer as the "second chapter". David tried not to think about his mother's cancer because it reminded him of his brother and Barbara's suffering reminded her of Peter's ordeal. Discussing her struggle to eat she said: "...When they force me to eat, I know how I feel inside because that's what Peter was going through". It appeared that the family were still grieving Peter's death and could not focus completely on Barbara's cancer.

While the Naran family cared deeply for each other, they appeared to have counterproductive coping mechanisms. As discussed, Simon, David and even Frank all helped with caring chores and it was important for them to care for Barbara. When Barbara lost her hair due to chemotherapy, Simon shaved his head in empathy so that they became "twins". However, the family had a myth regarding being 'strong' and not revealing their emotions that prevented them from sharing their difficulties with each other. When the doctors informed Simon that

Peter would die, Barbara reported that he didn't tell her because he wanted her to be able to be strong. While Simon did this to protect her, it was difficult for her to accept and they were in marriage therapy for a long time after Peter's death. Barbara also reported that Frank was experiencing academic difficulties "...because they (i.e. the family) don't talk about it".

Frank preferred not to talk to other people about his problems because "...they may even laugh at you..." When he needed to, he rather spoke to David who he saw as his best friend.

For Simon it was important that even if "inside its tearing us, but outside we show a normal side to the world". David also repeatedly stated that it was important to appear to be coping.

Discussing the importance of family members "being strong for each other", David used the metaphors of a chain and a glove:

(David): You see, you get as a family perspective; forget about the neighbours and all that. If my brother as a person broke down completely... seeing my father breaking down, how am I supposed to react? You understand where I am coming from?

(E): Ok.

(David): He is the head of the family (if) he breaks down...

(E): So he has to carry everything?

(David): He has got to be strong.

(E): Then you have to be strong?

(David): For me to be strong, for him to be strong, it's a chain.

(E): Ok.

(David): You understand? If you break a link off, the whole link is weak.

(E): Do you feel you have to be strong for your mother?

(David): Ja, its like, see, you look at it, the five fingers in the hand?

(E): Ja?

(David): For a glove to fit properly you got to have five fingers.

(E): Ja?

(David): If you take away one, the glove is not going to fit properly, is it? It's the same. Its five people here. Break off five then the family isn't strong any more. It's the fifth that makes the impact....

(E): So then none of you can break down because that will really...?

(David): I mean we can break down if we got each other to console each other, but if he went now and then there is going to be nothing for him because he has got to be strong for me to be strong. If I can break down, he can console me because it's fine. How do I console him? Understand he's supposed to be the head; he's got to be strong for us to be strong.

From the above it appears that it was important for the family members to be strong for each other. This was a hierarchical arrangement; Simon could not be 'weak' (i.e. express emotion

or reveal that he was struggling) because the rest of the family depended on him. Elsewhere David discussed that he had to be strong for his brother and sister. Simon also said that the family never spoke about their difficulties and that he was glad that I initiated this discussion: "I love it. I do love it. Because it's not coming from me. I am not making him (David) scared". It appeared that the family were concerned about being 'strong' for each other, not sharing their difficulties with each other. This appeared to have increased the burden on family members such as Simon. Furthermore, Barbara's cancer appeared to have reminded and retraumatised the family regarding Peter's death.

b SOCIAL SUPPORT

The Naran family were reluctant to access social support. They had no support from relatives, as none lived nearby. They were suspicious of others and felt that they did not care about Barbara. Frank was reluctant to talk to others fearing that they might "laugh" at him and thus preferred to talk to no one but David. Both Simon and David felt that other people were unable to understand their difficulties. Discussing this Simon said "...no one can really understand our problem and it's like I just sit here, understanding our problem". Barbara also expressed concern regarding Simon's lack of friends and socialising. The family were thus quite isolated.

However, other people tried to help the family, despite the family's misgivings. If anything, other people were over-supportive. The following conversation emerged during a discussion regarding neighbourly support:

(Simon): So we was frightened to go tell people around here, hey, what my wife got cancer. Oh. Then you know we really took it, and we reckon, bugger this, you know, this is us; let's fight it, we can tell the people....so this what happened. Yes people came in our area that heard it. They did come to us, they did give us, you know, what when people heard it was cancerous. A few were sending, like food, like as you know as my wife is going to die tomorrow...

(Barbara): They used to cook, I used to tell (the) Sister... about it, they used to cook food to say, like you know...

(Simon): Like maybe something is going to happen, like. You know, just like that. Honestly.

(Barbara): It was scary for ... (the family).

(Simon): It was scary for us.

(Barbara): It was very scary.

(Simon): They were just rushing things with us.

It appears that while others tried to support the family, they were overwhelmed by having the seriousness of the situation reflected back to them by support from others.

While the Narans appeared to be wary of others, there were certain people that the family felt able to access for support. Barbara and David felt that David's friends were extremely supportive. They were very compassionate about Barbara's hair loss, describing it as fashionable. One of them had a shaved head and joked that together with Simon they looked like "triplets". He offered to lend her some of his hats. Barbara also felt free to talk to their parents if she needed to. The family also felt supported by a local NGO. They frequently mentioned a social worker from this organisation, citing her opinions on various matters. Barbara felt that they could access her and the NGO any time they needed to. She described her as "...a mother to us all". David's friends were also described in family terms. Discussing his friends he said, "...my mom and dad is like their parents". Thus, while the Naran family were generally suspicious of outsiders, they feel able to access some outsiders for social support. These people appeared to be seen as an extension of the family.

c MEANING FACTORS

The Naran family's experience of Barbara's cancer appeared to be largely a reliving of their experience of Peter's cancer. As a result Simon and David in particular equated cancer with death and hopelessness. Simon frequently made the distinction between "knowing" and "unknowing", referring to conditions where one is certain or uncertain whether an ill person

will die or not. He stated "...cancer is a knowing death...there is no cure..." Later when Barbara said that the family cried a lot when she was diagnosed with cancer, Simon said "like a funeral you know". Following an incident at the hospital where Barbara nearly died, they also associated the hospital with death and pain and thus tried to avoid it. These negative associations interfered with the family's willingness to access medical treatment for Barbara.

There were also several positive meaning factors for the family. While "being strong" and not talking about their suffering had drawbacks, it also gave them a sense of purpose. Simon and David felt that they were being strong for the rest of the family and hence their suffering had meaning. Furthermore, Simon made several references to God during the interview.

Discussing the family's struggles, he said "...He's given (this to us), he wants to see how we going to take it". Later he prayed: "God you are there for us. So we are fighting in His strength". Barbara questioned God why this happened to her. The Naran's belief in God gave Simon and Barbara a sense that there was a purpose and meaning to their suffering.

Furthermore, Simon felt able to access God and his "dead people" for help, giving him a sense of control. The family's meanings and associations thus appeared to have both improved and hampered the Naran's ability to cope.

d STIGMA

The Naran family did not report any experience of stigma. While they preferred not to, they felt able to freely talk to others about Barbara's cancer and could easily access social support.

4.1.2.3 Summary

The Naran family appeared to be struggling. Barbara's cancer served to retraumatise them about Peter's death. This event had depleted the family's savings and left them struggling to cope with the expenses involved in Barbara's treatment. The family also struggled to cope

with other aspects of Barbara’s cancer. Barbara had many care-related needs and was unable to do any housework. This left the family, and especially Simon, struggling to provide for the family, care for Barbara and perform household chores. Barbara also struggled to adapt to the impact that cancer had on her body and appearance. Simon felt that at work he was constantly worried about Barbara. David and Frank exhibited symptoms of increased anxiety. The family however, felt that it was important to be “strong” and not show others and each other that they were struggling.

Other people appeared eager to help the Naran family. The family were overwhelmed by visitors and gifts of food when they initially informed people of Barbara’s cancer. Simon also received a lot of help and understanding from his company. A local NGO offered the family a lot of support. Thus, while the family were struggling, others offered them a lot of support. They were however, reluctant to access all the support that was available to them.

4.2 Families caring for a family member with AIDS

4.2.1 A family where the breadwinner is the patient: The Govender family

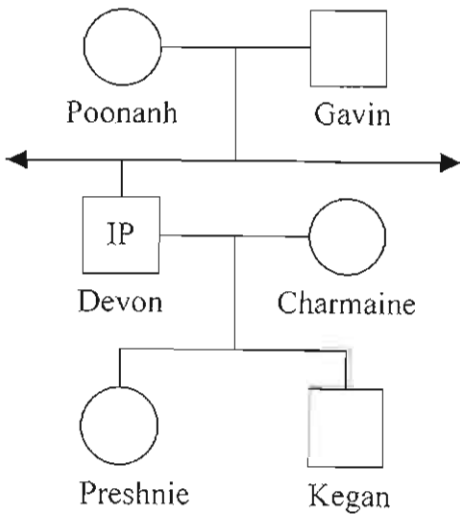


Figure 4: The Govender family.

The Govender family had many difficult experiences during the preceding 6 years. This began when Devon was hijacked, brutally attacked, sodomised and left bleeding and naked next to the road. He began to become ill 3 months after this incident. Doctors attributed his health difficulties to smoking, drinking or pancreatic complications. This was frustrating for Devon as he had always lived what he felt to be a religious and moral life, neither drinking nor smoking. Following a blood test for a life assurance policy 2 years later, Devon was diagnosed with HIV. This discovery came as a tremendous shock to Devon and Charmaine.

The Govenders were a very close-knit family. While they struggled financially, they appeared happy and cared deeply for each other. They appeared to be coping well, but had struggled during the previous few years. At the time of the interview Charmaine and Preshnie had become involved in HIV/AIDS counselling and the family had all appeared on television to discuss HIV/AIDS. Devon was regularly asked by different organisations to give presentations about his experiences and HIV/AIDS. Below are summaries of how the different themes were manifested in the Govender family's experience.

4.2.1.1 Stressors

a FINANCIAL

Devon's HIV had a dramatic impact on the family's finances. Devon used to work as a supervisor at a textile company, earning between R4 000 and R5 000 a month. Discussing this time, Devon said: "...we did have money and (we) used to spend, you know lavishly". He was medically boarded when he became ill and the family experienced a dramatic reduction in income. Charmaine, who worked at the same company, then became the family provider. At the time of the second interview, she earned R441 a week, but had been informed that due to a slump in the clothing industry this would be reduced by R100 a week,

adding up to a total of just over R1364 a month. This was supplemented by Devon's intermittent earnings from speaking about HIV/AIDS, money Devon borrowed, and money received from concerned relatives. However, Devon resented giving presentations to earn money because he felt he was being used and then forgotten. Despite all these sources of income, the family did not have enough money to meet all their needs. They stopped eating lunch and could not afford to provide Devon with a healthy diet, vitamins or medication, which they could obtain from a local hospital for R40 a month. Discussing their financial difficulties Charmaine said, "I am telling Devon like, you know, you'll have to go look, do something and you know, just to make little money maybe for bread. Not for, we don't need lunch really. Just the little, you know that we need". The reduction in the family's income has left them unable to meet all their financial needs.

b CARING

The family struggled to care for Devon. It took a long time to obtain a diagnosis, despite consulting several doctors. He was only diagnosed after two years, leaving Charmaine concerned that she too could be infected, but fortunately she wasn't. Devon then became very ill. At one stage, his CD4 count dropped to 50, which was well below the count required to make the diagnosis of AIDS. He also lost over 10kg and vomited frequently, forcing him to carry a bucket wherever he went. He became depressed (see the section on psychological responses) and was unwilling to help care for himself. Discussing this period, Charmaine said: "We used to actually carry him and say come because he never used to want to go. And the medication, he never want to take and that used to upset me. He just want to lie there, on the bed...". Devon's mother, Poonanh, cared for Devon during this time despite her own struggle with cancer because Charmaine had to work. Devon reported that at times neither of them was strong enough to get out of bed. When Devon was eventually placed on a drug trial, he reported that it damaged the nerves in his legs, leaving him unable to stand for long

periods of time. Due to the pain from this medication, he was reluctant to use any more. The family also did not have money to provide him with medication, a healthy diet or vitamins to keep him well. It thus appears that it was difficult caring for Devon and due to the family's financial difficulties they were unable to meet all his care-related needs.

c ROLE CHANGES

The family needed to make several role changes adapting to Devon's illness. Devon could no longer work, forcing Charmaine to become the family provider. This was difficult for her, as she could no longer spend as much time with the family as she used to. Charmaine reported telling a nurse running a therapeutic group while she was hospitalised (see 'psychological responses'):

I said I want my life back; I want to have my family life. And I don't have that now because I'm the one who has to work and work. On a weekend and you know, like I cannot have, you know, pleasures, you know, time (with) the children. I have to work seven days a week if there is overtime. I cannot say I am not going to come to work. I'll have to work and it was like a, you know, I had to work, work, work. I needed the money and you do not have the time together with the children.

Charmaine's transition from carer to provider was difficult. Due to this change Poonanh had to assume the caregiver role. The children also experienced a change in their responsibilities.

Preshnie said:

...before he get sick. He used to do everything for us, even like the school projects and assignments. My father used to go to the library to get information, so we were spoilt, you know, my father used to do everything for us. And then when he fell sick, then we had to do that. And it was hard, you know, I mean, my father used to go to the bank, get money and stuff and then we had to go do that....we had to pay accounts....we had to buy stuff; we had to go do that....we had to like do things on our own and we had to learn, you know, how to do it on our own.

All these role changes were difficult for the family members concerned.

d ACCESSIBILITY OF MEDICATION AND TREATMENT

The Govender family struggled to obtain medical care for Devon. Initially obtaining a diagnosis was difficult, with doctors attributing his health problems to various causes. Once

obtained, Charmaine felt that Devon's diagnosis obstructed him from obtaining rapid treatment. Discussing an experience at a provincial hospital, Charmaine said, "As soon as the doctors, they see him, then ok, you can wait and they will check the next person, you know. They will just leave him aside". The hospital did not initially cater for HIV positive people, which was possibly due to the Department of Health's policy not to provide antiretrovirals (see the Literature Review for more information on this policy). They had a clinic for cancer but not for HIV. According to Devon:

That was difficult...when I went to (a local provincial hospital) and they like was saying and Doctors were saying there is no place for HIV positive... Like we went to hospital in the morning and were treated the next day just with a drip. It was a devastating time, and I was lying on a stretcher and...the whole family was sitting all night at the hospital and they said there was no place for these HIV people.

In order to obtain treatment for Devon, they tried more than four hospitals, a Hindu temple, a traditional healer and attending church (see the section on 'meaning factors'). An HIV clinic was eventually established 6 months later at a provincial hospital. Here Devon finally obtained help. Charmaine said, "...They were actually like a family". Devon found a doctor at this clinic very supportive and helpful. Devon was also placed on drug trials. A drug was recommended to him that he could obtain cheaply through the clinic for R40 a month, however, the family felt unable to afford this or the diet that was suggested. Thus, while the family initially struggled to obtain medical care for Devon, they were eventually able to find care for him. However, they were unable to afford adequate medical care.

e UNCERTAINTY

The family faced uncertainty on a number of occasions. They struggled to discover the cause of Devon's health problems. There was also a chance that Charmaine too was infected. Discussing this she said, "...The scary part was – you know like, whether I am infected...because the possibility was there...we went for the tests and it was negative. Thank God for that". Devon's experience of HIV was marked by variable health. While his

CD4 count was approximately 800 at the time of the interview, it had been much lower, suggesting a severely compromised immune system. While Devon's health was good, it could deteriorate at any point. The family experienced these uncertainties as stressful.

f PSYCHOLOGICAL RESPONSES

Devon's infection had a significant impact on the entire family. Devon and Charmaine initially denied that he could have HIV and obtained a second and third opinion. Poonanh refused to believe that Devon had HIV: "God, my son haven't got....I not believe. I say my son haven't got..." She believed that Devon lived a good life and thus could not have HIV. After his initial denial, Devon became depressed. Discussing this, he said: "that was the end of me, you see, so I was so frustrated...just lying in bed, you know, not doing anything you know... (it) was worthless me living". During this time, which lasted approximately 3 years, Devon felt he had no energy, didn't want to see people, had sleep difficulties, stayed in bed all day and felt suicidal. Devon and Charmaine reported having many fights during this time.

Charmaine had difficulties coping. She made two suicide attempts and was also hospitalised twice in a psychiatric unit for depression. Prior to this she had made a suicide attempt when she was 15. Charmaine said that it was difficult for her to work 7 days a week and lose the contact she used to have with her children (See section on 'Role changes'). During her second hospitalisation she was forced to leave after 3 weeks in order to work. Furthermore, Charmaine reported that since Devon's diagnosis she began to get headaches. The emergence of these headaches at this difficult time suggests that they were stress related. It appears that the period following Devon's diagnosis was difficult for Charmaine.

Devon's illness was also difficult for the children. Preshnie reported that when their father was ill they became very "stubborn", not listening to their parents. Her parent's fighting made

it difficult for her to concentrate on her schoolwork. However, she kept her problems to herself: "...I never shared it with anybody else but I kept everything to myself and I never showed it". She managed to sustain her above-average academic performance. Kegan however, could not contain his distress. Devon noted: "From when I was sick he doesn't perform that well at school". Kegan was close to his father and Charmaine said that before Devon became ill they did everything together. He felt abandoned by his parents repeated hospitalisations. Charmaine said he once tried to kill himself on his birthday by running into the road and had to be restrained by his uncle and grandmother. Speaking about this incident, Kegan said: "Um, it was difficult, um seeing my father in hospital. Him dying so. And every time, either when my mother or my father was in hospital, it's always my birthday". It appeared to be difficult for Kegan and the other family members to cope.

4.2.1.2 Mediating factors

a FAMILY ABILITIES

Prior to Devon's illness the family unit was not very cohesive. He worked 7 days a week and Charmaine and the children would visit her parents on weekends without Devon. There was also a lack of communication in the family and the children were not informed of Devon's diagnosis. Since Devon's conversion to Christianity, the family felt that they became closer. They all felt that even though they didn't have much money, at least they had each other. Discussing this, Charmaine said, "...my uncle and my brother, my brother earns about 8 to 9 thousand, but they don't have that uh...the thing, what we have". She felt that the quality of their relationships was more valuable than money. They did everything together, according to Charmaine "...we don't go anywhere without each and other. If we have to go somewhere, the four of us will go together". Preshnie said even at church they didn't like to sit apart. They also began to communicate more with each other. Charmaine said "...Like in the

evening, we must sit on the bed, we never had that all that, we sit and we like have fun with each and other and we can actually, like you know, talk about life". The family became closer over the course of Devon's illness and also learnt to communicate more freely. This appeared to have helped them to cope.

b SOCIAL SUPPORT

The Govender family initially struggled to find social support. They could not find other people living with HIV or counselling support for people with HIV/AIDS. Furthermore, while working Devon wore earplugs and was unable to communicate with others. He lacked a support base of friends, having few friends and preferring to stay home. Furthermore, support from the broader family was not always helpful. Charmaine reported that her family was understanding of Devon, but failed to notice that she was struggling. Devon's brother upset Charmaine by asking her why she stayed with him if he was ill. Two of his brothers also committed suicide, which proved to be a strain on the family. At this time the Govenders felt that they lacked support.

After their initial struggle, the Govenders eventually managed to obtain help. They found a cancer counsellor from a local NGO who had to pretend that Devon had cancer in order to counsel him. Eventually she could no longer help them and put them into contact with a nurse from another NGO. Through her they obtained a lot of support. She found the HIV/AIDS clinic at a provincial hospital and helped them to register there. The family felt that they could access her whenever they needed to. Discussing her help, Devon said:

...when she came as a counsellor, she was everything, she was a doctor, she was a, you know, like everything...like she can give you, she can get medication for you and she, you know. She can do something if we tell her, you know, if you tell her, you know, my leg is painning now, somehow or other she is coming the next, she is coming with something.

She even took Devon and Charmaine to hospital. She asked the nurse at Charmaine's company to check on her because she was going through a difficult time. Devon said that she sometimes contacted them by phone to check on them. When discussing her they often used positive religious metaphors to refer to her. Devon referred to her as an "angel". Devon and Charmaine repeatedly suggested that she was doing God's work and felt that she had been very helpful to the family.

Preshnie also experienced an increase in social support. Initially she spoke to no one and did not let anyone know her father had HIV. Then she appeared on television discussing what it was like having a father living with HIV. Talking about this event she said:

Well at school nobody knew and then after that, like I told everyone that I was going to be on TV and stuff like that but I didn't tell them why. And so like I was scared, like you know, the day they were going to watch what their reaction would be to me... but then the day came and they all approached me and they told me that they admired me for my, you know, for my uh me going and doing it...

Preshnie and the rest of the family decided to be open about Devon's HIV and Charmaine felt that it was much easier being open. While the family initially struggled to obtain social support, they did eventually find it.

c MEANING FACTORS

Various meaning factors affected the Govenders. Religion was important to the family.

Devon initially regarded HIV as a punishment from God and questioned why He allowed him to become infected. Devon felt that because he had lived a moral life it should not have happened to him. He soon felt life was meaningless and became depressed. When the Govenders began attending a charismatic church, Devon's mental and physical health improved. Discussing the impact of Christianity on his life, Devon said:

...accepting Lord Jesus Christ in my life and you know and taking him into my heart like and you know and that's what cleared my mind. Like you know, and I felt strong like...I really, you know, like felt like, like, like that I have been healed, properly healed like.

And, you know, I got my strength back and I can do things that I, you know, I can do things for my children, that I can go wherever I want to go. Like you know, those kinds of things like, not lying in bed.

The improvement in Devon's mood was seen as a miracle in the family. Aside from the changes in Devon's health and mood, the family credited Christianity with curing Devon's father's alcoholism and improving the closeness and communication of the family.

Discussing her experience, Charmaine said, "I started going to church, and that's where I found help. The strength and like the courage there and messages like, you know, "Never mind, whatever you going through, but God loves you and he cares for you." And I really tell you that's what brought (us) up. If I wasn't going to church, I don't know where I be..."

Christianity appears to have given the family a sense of hope and meaning.

Christianity offered more hope to the family than medicine. When Devon discussed HIV, he usually implied that he would die or become ill because of it. At other times, Devon believed that he was cured. Discussing this, he said "...I know for sure that I am healed now, I am only waiting for the Doctor to say: "you know what, uh, you're...there is nothing wrong with you, you are fine". This appeared to reflect a wish to be well again. Christianity offered Devon hope that medication could not offer.

The family itself also became very important. It was seen as being more important than financial well-being (see the 'family abilities' section). Charmaine said that wanting to care for her children helped her get better during her last hospitalisation:

...like thoughts were going in my mind. I am so selfish; what about my children, I'm saying, I'm feeling like this and I'm feeling like that. What about my children? They also...going through such a rough, who they going to talk to? I say I am going to talk, you know like, I need somebody, what about them? At least me being there, you know, will be a help for them, that's how I come out of it...

Having each other and caring for each other gave the family a sense of meaning.

A final source of meaning could best be described as ‘political’. The family had HIV/AIDS concerns beyond the family. Devon regularly gave presentations on HIV. Family members had also appeared on television on various occasions discussing their experiences. They were concerned about HIV infected children, medication, diet and young married couples who were unsure about their partner’s infection status. Charmaine and Preshnie were training to be volunteer HIV/AIDS counsellors. Devon expressed the family’s concern for others as follows: “Ja, like we did worry for the people because we know what we are going through”. Because of their own struggle with HIV, the family felt concerned for others going through the same experience.

The family’s religion, their love for each other and their concern for and involvement in various HIV-related issues gave them a sense of meaning that helped them to endure their experience.

d STIGMA

The family encountered stigma in several different forms. Devon and Charmaine noted that others generally associated HIV/AIDS with sexuality “(Devon) What I am saying, this disease...is 99% sexual contact. (Charmaine) Ja...now you know like a when a person is infected, they talk so bad things”. Possibly due to this Devon and Charmaine struggled to find other families with HIV as they may not have felt comfortable discussing it openly. It has also been noted that Charmaine felt that doctors gave them second-rate attention when they discovered Devon had HIV. This made the Govender’s illness experience more difficult.

While the Govenders encountered stigma outside the family, they also exhibited prejudice about HIV. Because Devon lived a moral life it was felt that he should not have HIV.

Poonanh refused to believe Devon had HIV: “I say my son haven’t got...people talk. If that bad person got ...go away with the women, ja, I can say (they have HIV)... (But) he don’t go, he work at the house”. Charmaine said:

...actually, we used to lie to the children and, you know, people around us, that he had cancer. Because, a like, Devon was a person like when I was telling you, like nobody would believe it that he had it that sickness and, you know, now, those days when, when they talk about HIV positive, you know, you were sleeping around, you know....so that’s why,...you know like he couldn’t like tell exactly what was wrong with him.

The family appeared to associate HIV with immorality and promiscuity. It was thus necessary to express to others that Devon had cancer because having cancer was socially and morally acceptable. It was interesting to note that Charmaine referred to the process of Devon accepting and becoming more open about HIV as “coming out”; a term used among homosexuals to describe the process of becoming open about their sexuality. HIV infection thus appeared to have a lot in common with belonging to a sexual minority group. However, it seemed that stigma was not just an external process, but a family process too.

4.2.1.3 Summary

Devon’s illness had a dramatic impact on the family. He was the family’s main provider, but was unable to continue working when he became ill, bringing about a reduction in the family’s income. This forced Charmaine to become the provider and Poonanh to become the family caregiver, despite her own struggle with cancer. Other family members also experienced increased burdens. It was initially difficult for the family to obtain medical help and social support. They felt that doctors gave Devon second rate treatment when they found out that he had HIV. Furthermore, the family struggled to reconcile HIV, its association with promiscuity and Devon’s moral life. Despite all their difficulties, the family converted to Christianity, became involved in various HIV-related issues and became closer during the course of Devon’s infection. These factors gave the family a sense of meaning which helped them to cope with Devon’s illness.

4.2.2 A family where the caregiver is the patient: The Moodley family

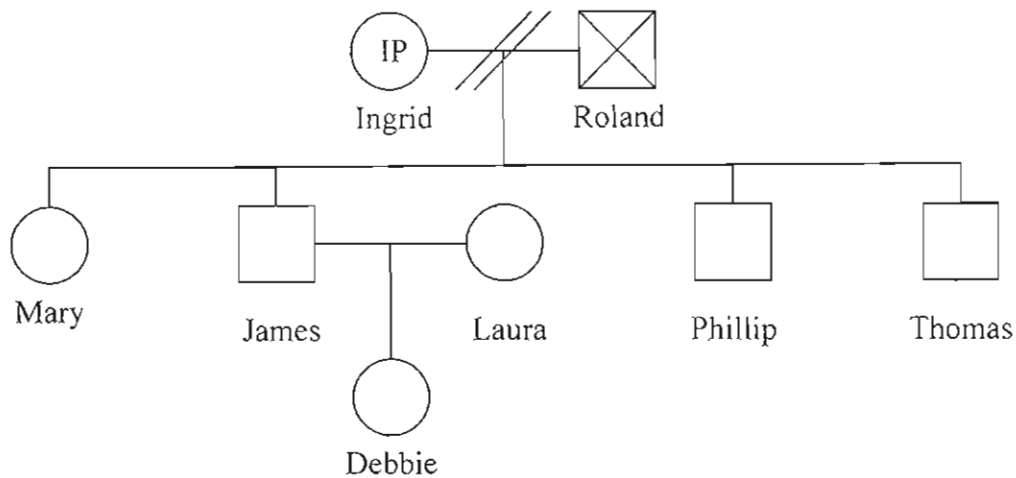


Figure 3: The Moodley family. Ingrid and Thomas were still living together.

Ingrid and Thomas Moodley lived in a small house that was almost bare inside. They were very hospitable and while it appeared that they did not have much money, Ingrid insisted that Thomas buy a bottle of coke for their guest. They did not however, share any of it with me. Much of the general conversation before and after the interview involved the cost of goods and where good bargains could be found.

Over a year prior to the interview, Ingrid began to become ill all the time. She visited several doctors but none of them could discover the cause of her difficulties. Eventually she developed oral thrush that made it impossible for her to swallow. Her sister took her to a private hospital where a number of tests were performed and she was informed that she tested HIV positive. Since then she had various other health problems including shingles which left her scarred, and frequent headaches. She also became increasingly aggressive.

Below is a summary of how the different themes were manifested in this family:

4.2.2.1 Stressors

a FINANCIAL

The Moodley family had serious financial difficulties which predated Ingrid's diagnosis. Ingrid and Thomas blamed Ingrid's siblings for most of these problems. According to Ingrid: "...I have been robbed...I had a shop and after my father died it was supposed to be mine but then my brothers took it away from me". Thomas stated that this happened approximately four years prior to the interview. Furthermore, Thomas said Ingrid's siblings left her with a lot of debt; including a R40 000 bond on her house that Thomas had to leave school to repay. He was extremely angry with the broader family. A business venture that Ingrid attempted also failed. She believed that her business partner and lawyer cheated her and as a result she lost her house and furniture. These difficulties left the family financially crippled.

The Moodley family did not have enough money to cover their expenses. According to Ingrid and Thomas they could not afford to pay for medication. She had a course of Combivir (an antiretroviral drug regimen) that she was given as a present by her brother, however, at a cost of "R1080" a month they were unable to afford it themselves. She took half doses in order to prolong the treatment. They were also not able to afford food without the help of Ingrid's sisters. While discussing the help they received from her brothers and sisters, Ingrid said "Ja well I get a little bit from you know my sisters and that, but not enough, but it keeps you going". At the time of the interview she was waiting to receive her first pension payment. This would help the Moodleys with their overwhelming expenses.

b CARING

Ingrid reported that before she was infected with HIV she had been very healthy. While possibly exaggerating, she insisted that she had never even taken a tablet before. Since

becoming infected she developed numerous health problems, including oral thrush which prevented her from swallowing, shingles that left two centimetre scars covering her body, diarrhoea lasting two days, memory problems, constant tiredness and severe headaches.

Discussing her headaches, Ingrid said:

...I get very tired. Very tired and I just want to be by myself. You know. And then when (Thomas) comes and he talks and I can hear his voice in my head. Because I have got this headache. I get headaches very frequent. I never got headaches in my life, but these headaches are sort of like...like you know terrible from here to here (indicates across her forehead).

Ingrid not only had to cope with her many health problems, but she had to care for herself.

While Thomas was concerned about Ingrid, he was also worried about the risk of infection:

(E): You are almost saying that you are kind of scared about getting infected and stuff like that.

(Ingrid): Mmm.

(Thomas): Yes. Very scared.

(E): Like things like using the same toilet, using the same glasses?

(Thomas): Ja.

(Ingrid) Ja, he is very scared.

(E): Cooking?

(Ingrid): I cook.

(Thomas): I am a bit scared too. I am frightened to eat.

(Ingrid): Very scared to eat.

(Thomas): But now they say you can't get it, only blood contact?

Thomas was unsure that transmission could only occur through blood and sexual contact.

Ingrid stated that he even kept a separate set of blankets to sleep with. Thomas and Ingrid also discussed different scenarios such as if Ingrid accidentally spilt blood on the ground, could Thomas become infected if he stepped in it? They also made various inquiries such as how long HIV could survive in air and could the virus be transmitted via bedclothes. These questions suggest that the Moodley family, and Thomas in particular, were concerned about the risk of infection. This forced Ingrid to care for herself.

c ROLE CHANGES

Being healthy all her life made it difficult for Ingrid to make the transition to the sick role.

When asked if she had ever had headaches before, she replied:

No, no, no I never was sick. I (have) never taken a dispirin in my life. I was a very strong woman, I was very strong. I (have) never taken a tablet in my life. I could walk like a man and I never got even a flu or something. I was lucky all my life.

For Ingrid becoming HIV positive was difficult as it was difficult losing her health and assuming the sick role.

d ACCESSIBILITY OF MEDICATION AND TREATMENT

Ingrid had difficulty accessing medical treatment and at times rather utilised traditional treatments. When she first became ill she struggled to get a diagnosis and obtained help from a pharmacy. Once she went to a doctor who gave her an injection without any explanation. Eventually her sister admitted her to a private hospital where tests were done. There they treated and cured her oral thrush, informed her that she had “AIDS” and discharged her. The family did not have enough money to afford medical treatment. The only treatment that she had had was the Combivir that she received from her brother. Ingrid had not yet explored what treatment hospitals would provide, but was planning to explore this option. The Moodley family had however, been able to access traditional remedies easily.

For the Moodley family, traditional herbal remedies appeared to be an adjunct rather than an alternative to medical treatments. While believing in the efficacy of Combivir, Ingrid also believed a particular herb helped improve and maintain her health and could even cure her. Family members, including her herbalist grandmother, had been using it for many years:

...and this herb was taken over the centuries in the family, also... (a family member) was diagnosed (with cancer). My cousin's sister was diagnosed with cancer of the womb. And she took that (herbal remedy) and she was better within six months and she went back. The doctors tested her negative...

She believed that the herb had limited her diarrhoea the previous year to two days. As this herb was indigenous to the area, it was unlikely that the family had been using it for centuries. She may have exaggerated in order to increase the value of the herb so as to give herself hope. Furthermore, while Ingrid found relief from oral thrush in hospital, she did not hesitate to use another traditional remedy to eventually cure her shingles. These herbal treatments were more accessible than medical ones and extended the range of therapeutic possibilities available to her.

e UNCERTAINTY

Ingrid and Thomas appeared uncertain about many aspects of her illness. Initially she struggled to find the cause of her poor health. After being diagnosed HIV positive, she was not sure how she got infected, how long she had been infected and even how sick she was. Although she had the results of her last blood test, she did not know how to interpret them and eagerly sought help from me during the interview. They were also not sure how Thomas could become infected from Ingrid. Finally they were not sure if Ingrid's health was improving since she started using the herb or even if it might cure her. It appeared that while the family were plagued by many uncertainties, some were caused by lack of information. With the family's consent, further counselling and education was arranged for them with an NGO to address this.

f PSYCHOLOGICAL RESPONSES

Ingrid's illness was difficult for her and had a significant impact on the family. They practiced denial strategies that helped them cope with the stigma and hopelessness of HIV. Discussing how she became infected, Ingrid was unwilling to consider that she may have been infected sexually and instead she and Thomas preferred to believe that she became infected helping people injured in fights at the bar she used to run (see the 'Stigma' section

for further discussion on this topic). While this could be the case, it was also possible that she became infected by sexual transmission from a boyfriend or her husband who died from a mysterious illness. Furthermore, while the herbs Ingrid had been using may have helped her, it also served the function of offering Ingrid a greater margin of hope than medical treatments and also offered a denial of her inevitable death. These practices offered more hope and made Ingrid's HIV status more bearable.

It was hard for Ingrid to accept the way that HIV affected her body. Shingles left her with visible scars covering her body and she appeared to be very conscious of these. She also gained weight: "I was 56, and I have gained ever since I...I was 56, I was slim. I am gaining. I am now about 70. I am gaining...I was always slim. Very, very slim". Finally HIV made her feel "dirty": "Every day I go into the bathroom and scrub myself thinking this germ would come out. I don't feel right to eat, I feel like dirty. I feel no matter how I bath this germ's not going to go away". Thus, the way Ingrid perceived her body changed; she had become less comfortable with her body.

Ingrid also began to experience severe headaches that made her more irritable. Discussing this, she said:

Yes it does frustrate me. Even if (Thomas) talks a bit loud I cannot control my temper, I get irritated because I got this headache and he is talking to me and while he is talking to me his voice is getting in my head. Even if he takes a spoon and eats and makes a noise with it, it irritates me. I get easily irritated.

This was difficult for Thomas who had to deal with his mother's anger. Thomas however, generally appeared to be coping well, but was very concerned about becoming infected.

4.2.2.2 Mediating factors

a FAMILY ABILITIES

Ingrid's children did not cope well with her diagnosis of HIV. While they were concerned about her, she reported that they did not know what to do. Prior to her diagnosis, her son James, his wife and baby lived with her. Ingrid and Thomas believed that they moved because James was scared of the infection risk to his wife and daughter. Thomas, who was living with his uncle, moved back to his mother because he was concerned about her. Phillip responded to his mother's illness by saying that she shouldn't tell anyone because of what they may think. Aside from Thomas's concern for his mother, the family generally did not respond well to Ingrid's illness and were very unsupportive.

b SOCIAL SUPPORT

The Moodley family did not obtain much support from their family, but managed to obtain some from a local NGO. They had a bad relationship with Ingrid's broader family which preceded her illness and they did not feel supported by them. Discussing Ingrid's family, Ingrid and Thomas said the following:

(Thomas): They cannot be bothered. That is the family we come from.

(Ingrid): Each one is for themselves, you know they...

(E): So you guys are not really very well supported by the family at all?

(Ingrid): Yea, because right now nobody even phones.

(Thomas): Because we had everything and (they) just went you know, they took it...

They minimized the help that they did receive from Ingrid's family. It was not seen as significant that Ingrid's sister had admitted her to a private hospital to treat her oral thrush and investigate her health problems. The Combivir that was given to her by her brother was also dismissed. Ingrid also viewed the food that her sisters bought for them as insufficient help: "Ja well I get a bit from my sisters and that, but not enough, but it keeps you going. What can you do?" The Moodley family did not feel well supported by their broader family.

In sharp contrast with the way that the Moodleys felt about Ingrid's broader family, they felt well supported by a local NGO. Discussing this, Ingrid said:

They are very good. They are very supportive. Really, I mean nowhere in the world that you can get people like that. They are very good. Very good... Ja you can talk to them, even when you are sick they come and sit here and they see to you. Like if I am sick. I have been phoning my sister.... I was not well these last few days I was feeling giddy and I have been phoning my sister-in-law too because I don't know where to phone to tell her that I am not well and in turn she said, she, her daughter answered the phone and she said I will phone you in 10 minutes time and I will phone you in 5 minutes time. Every day three days I have been phoning and she never phones. You see that hurts, she didn't phone...the (NGO) is the only place that really helps you. (They are) the only place that you can phone and say I am sick and they even phone you and ask you "How are you?"

While the Moodley family did not feel supported by Ingrid's family, they did feel supported by the NGO. It appeared that they were able to give the Moodleys the support they needed.

c MEANING FACTORS

HIV had a significant impact on Ingrid's perception of the future. While discussing whether the family could deal with her illness, Ingrid stated fatalistically "ja we try and deal with it. What are we going to do?" Elsewhere, discussing the same topic, she was more despondent:

Hopeless, The future's hopeless. You can't think about tomorrow or I am going to put a new pathway, I am going work, I am going to get a job...everything ends there where you got this. You got this you got no future...your future is sort of bleak. You can do nothing. You can't think about nothing.

It appeared that HIV represented a dramatic foreshortening of Ingrid's future. However, the herb that Ingrid was using offered her some hope since she believed this herb had already cured a relative of cancer. Discussing this she said:

(Ingrid): ...Full-blown AIDS give you about maybe a year to live...since (I) get sick it is about 2 years, I am still...(healthy).

(Thomas): Maybe something is happening?

(Ingrid): Because I am also taking this sort of herbs that is helping me.

Thus, while HIV appeared to represent a foreshortened future and ultimately death to Ingrid, her herbal treatment offered her some hope.

While Ingrid encountered some stigma, it was more significant that she distanced herself from any association between her illness and sexuality. When she was diagnosed with HIV she reported that she wanted to be open about it, despite her son Phillip's concerns: "...it was not worth lying. No because Phillip is the one (who) said that we cannot tell them that, you know, what is everyone going to think...?" While not wanting to hide her HIV status, she did avoid any connection between it and the possibility of sexual transmission. Ingrid said she was not sure how or when she became infected. Her ex-husband died of a mysterious illness and she had had a boyfriend with whom she was sexually active. The possibility thus existed that she may have been infected sexually. This possibility was raised and Ingrid immediately distanced herself from it and instead suggested that she may have been infected while helping clients at a bar she used to manage:

(E): ...I gather then, how did you get it, from your... (husband)?

(Ingrid) You know I don't know what to tell you...

(E) You are not very sure?

(Ingrid) How did I get it because the problem is I used to work I used to have a shop that used to be a sorghum beer shop where everyone used to get drunk and stabbed and they used to fight and I didn't know about AIDS then. I used to run and touch them with my hands.

Both Ingrid and Thomas continued to discuss how Ingrid often helped people who were hurt at the bar. While she may have been infected during one of these incidents, it is significant that Thomas and Ingrid distanced themselves from the possibility of sexual transmission and instead posed a scenario where she helped other people and was thus an innocent caring victim. It thus appeared that Ingrid and Thomas were uncomfortable with the association between HIV and sex, suggesting that they had prejudicial attitudes about STDs.

4.2.2.3 Summary

The Moodley family were very hospitable despite their difficulties. They had many financial and family problems which predated Ingrid's diagnosis. They struggled to obtain medical

help and could also not afford any medical treatment for her. It was difficult for Ingrid to come to terms with the changes in her body that were brought about as a result of HIV. She also developed painful headaches that she felt made her more irritable. She and Thomas distanced themselves from any link between her infection and sexuality. While Thomas was concerned about his mother, he was also very concerned about the risk of becoming infected with HIV himself. They felt that their immediate and broader family did not offer them much support. It appeared that the difficulties which the family had before Ingrid's illness contributed to the family's stress. However, the family did have some hope and support. They felt that a herb that had been in use by the family offered her some hope and felt that a local NGO offered them a lot of support. Despite this the family generally appeared to be struggling.

5 Discussion

5.1 Discussion of main findings

Each of the four participant families had unique circumstances, stressors, meanings and abilities affecting their experience of caring for their ill family member. Even families which appeared to be coping well were affected by this experience. However, it did appear that the two families caring for a family member with HIV had several additional burdens to cope with. These included a longer and more variable course of illness (which impacted on factors such as finances and caring), infection concerns, more difficult access to medical resources, less social support and stigma. However, it also appeared that at least for the Govender family, their involvement in various HIV/AIDS related concerns gave them a sense of meaning and purpose.

5.1.1 The impact of the chronic illness on the families

Every family responded to their family member's illness in a unique way and had unique factors affecting their experience. Despite these unique factors, there were similarities in the way that the families responded to the illnesses. It appeared that the illness brought about a number of stressors in the families which they responded to according to their individual abilities, meanings and resources. This corresponded well with both Hill's ABC-X model (1948 & 1958, as cited in Patterson, 1989) and the FAAR model (Baker & Patterson, 1989; McCubbin & Patterson, 1983; Patterson, 1989).

However, the ABC-X and FAAR models appeared to have several shortcomings. In terms of praxis it became difficult to distinguish between stressors and strains. Because of its reasonably discreet onset in terms of a family's experience, a chronic illness could be described as a stressor event, however, due to its chronic nature it also becomes a strain. This appeared to be true for other stressor/factors as well, such as financial difficulties. There may be few, if any, events which are truly discreet in nature; a condition which would be required in order to meet the FAAR definition of a stressor. Even events which have a discreet onset may continue to exert an influence over a prolonged period of time and may become strains. The death of a family member, which Patterson (1989) uses as an example of a stressor, may become a strain through the process of mourning. Stressors and strains appear to be interrelated. In this discussion, no distinction is made between them and the term 'stressor' is used to refer to both.

These models also did not clearly address the link between stressor events and their impact on the family. In this study it appeared that while the families were acutely aware of the illness of their family member, the impact of the illness on the family did not appear to be

direct. It appeared that these illnesses exerted their influences on families largely by inducing a number of stressors in the family. The sum of these stressors could be considered to be the impact of the illness on the family. The ABC-X model and the FAAR model did not adequately address these issues.

The families in this study all appeared to be confronted by a number of stressors brought about by their relative's illness. It appeared that the illnesses placed an increased financial and caring burden on families. Only the Mutara family reported a limited financial and caring impact. It was noteworthy that the caring impact was felt most acutely by female family members. This is congruent with the work of Marcus (1999) and Rait and Lederburg (1989). Furthermore, several role changes occurred in the families. It appeared to be particularly difficult for ill family members to assume the sick role. There were also often changes to the provider and caring roles in the family. Families occasionally had a variety of difficulties accessing medical treatment. Uncertainty, frequently regarding prognosis and symptoms, was also experienced as stressful. Finally, family members appeared to be vulnerable to various forms of psychopathology. The ill family member often had various body image concerns and symptoms of depression and anxiety appeared to be common among all family members. Many of the stressors were also responses to the illness. The families responded to these stressors differently, depending on a variety of mediating factors.

Mediating factors included the family's abilities, social support, a variety of meaning factors and stigma. These factors correspond roughly with factor B (family capabilities) and factor C (the family's definition of the stressor) of Hill's ABC-X model (1948 & 1958, as cited in Patterson, 1989) and the FAAR model (Baker & Patterson, 1989; McCubbin & Patterson, 1983; Patterson, 1989). However, it was felt that it was more true to the experience of the

participants and the nature of this study to define a 'mediating factors' category rather than to discuss their experiences in terms of the two above-mentioned factors, as both mediated families' experiences. Furthermore, in accordance with Hill's model and the FAAR model, 'stigma' would be understood as a strain. However, in this study it appeared to be an underlying factor which interacted with and mediated the experience of the family and was thus considered to be a mediating factor, rather than a strain. The 'mediating factors' referred to in this study thus do not correspond completely to factor B and C of Hill's model or the McCubbin model.

The mediating factors appeared to mediate the impact of stressors on the families by either improving or impeding the families' abilities to cope. Each family possessed their own unique abilities. In some cases these helped the family to cope, such as the Govenders' increased sense of cohesiveness, but this was not always the case. The Naran's concept of being strong for each other by not communicating their experiences freely with one another may have made it more difficult for them to cope. Factors such as these could be studied with the Olson Circumplex Model (Olson, Russell & Sprenkle, 1983) and the Beavers Systems Model (Beavers, 1989; Beavers & Voeller, 1983) as noted by Patterson (1989) however, as discussed in the literature review, these models do not address the variety of factors impacting on families to explain their responses to stress. Families' responses to stressor events appear to be more complex and multifaceted as argued by Patterson (1989).

Aside from the families' different abilities, they also had different experiences of the other mediating factors. The FAAR model (McCubbin *et al.*, 1980; McCubbin & Patterson, 1983; Patterson, 1983) postulates that social support acts as a buffer to the stress experienced by families. This also appeared to be the case for these families. Sometimes however, the social

support also appeared to be a stressor. Families had various levels of social support, ranging from little, to being overwhelmed by large numbers of visitors. It did however, appear that all the families felt supported by the NGOs through which they had been sampled. This probably reflected that to some extent families willing to participate in the study had good relationships with these NGOs. However, these NGOs all worked with people who were terminally ill and were thus associated with the process of death and dying. This may have made them more accessible to the families. For all four families these NGOs provided an important source of social support.

The families' abilities to cope were also affected by their own unique meanings. For the Naran family, Barbara's cancer was linked to their experience of Peter's death. This made it more difficult for them to cope. Religion and faith in God was another meaning factor. This helped the Govender and Naran families cope and gave them a sense of meaning.

Families also had their own individual experiences of stigma. Some families, such as the Mutaras and the Narans, did not have any experience of stigma. The Govenders and the Moodleys on the other hand had experienced stigma. This will be discussed further in the following sections.

It thus appeared that while the families' experiences were unique, they also shared common factors. It appeared that the illnesses brought about a number of stressors, which the families responded to differently according to several mediating factors. However, there did appear to be differences in the way that cancer and HIV/AIDS affected the families in this study.

5.1.2 The impact of caring for a family member with cancer

The two families caring for a family member with cancer had a wide range of experiences.

The Mutara family appeared to have experienced very little disruption in the family while the Naran family appeared to have experienced a tremendous amount of upheaval as a result of Barbara's cancer. It appeared that this was partially due to Barbara's illness retruamatising the family regarding Peter's death a decade before, and partially due to them not yet having moved into the post-crisis adaptation phase of the FAAR model (Baker & Patterson, 1989; McCubbin & Patterson, 1983; Patterson, 1989) as the Mutara family appeared to have done. Despite the variations in the disruption that these families experienced, and the differences in their experiences, they did share several common experiences.

There were differences in the level of the financial burden that the illness placed on the families. The Mutara family appeared to have experienced very little financial disruption. Harold's cancer appeared to have imposed very little financial demands on the family. The Naran family however, appeared to be struggling to cope, as Peter's death had already depleted the family's savings. Nevertheless it appeared that others were very sympathetic towards them. Their pharmacy extended their credit, allowing them to obtain medication, and Simon's employers offered the family a loan and employed David on a part-time basis in order to assist the family financially. Thus, while the Naran family appeared to be struggling more than the Mutara family to cope, they appeared to have a lot of help and support from others.

Both families appeared to obtain medical treatment with relative ease. After being diagnosed both Harold Mutara and Barbara Naran were immediately reffered for treatment at provincial hospitals. Both families managed to pay for their ill family member's treatment. Harold's

treatment was affordable within the limits of his pension. It appeared that these families also experienced the doctors as accessible. Barbara Naran's oncologist gave the family his toll free telephone number and insisted that the family phone him if Barbara felt ill. Medical treatment thus appeared to be accessible to these families.

A further concern for the Narans was that they were afraid that the family had a genetic predisposition for cancer. This was a matter of great concern to them, and in response to this they intended to have all the children tested for cancer. It appeared that since they had already experienced several cancer-related deaths in the family that they were afraid that yet another family member could die of cancer.

The Mutaras and the Narans had both had a large amount of social support. Both families appeared to feel able to discuss the cancer with others if they desired. The Narans found that others, such as the local pharmacy and Simon's employer, were very understanding and helped them a lot. However, both families had also been overwhelmed by visitors and social support during the course of Harold and Barbara's illnesses. They experienced this as stressful. Neither family appeared to have any experience of stigma.

It thus appeared that the Mutaras and the Narans had different experiences. While the Mutaras appeared to have experienced very little disruption in their family life as a result of Harold's illness, Barbara's cancer had a significant effect on the Naran family. While the Naran family had financial difficulties and were concerned about a genetic predisposition in the family for cancer, it was noteworthy that both families easily accessed medical treatment and also did not appear to have any difficulties obtaining social support and help. The

families caring for a family member with HIV/AIDS appeared to have difficulties accessing these resources.

5.1.3 The impact of caring for a family member with HIV/AIDS

While the families caring for a family member with HIV had to cope with the same stressors such as financial and care-related difficulties as the other families, they also had several additional factors impacting on them. These included a prolonged and more variable course of illness, fears regarding transmission, difficulties accessing medical treatment and less social support. These appeared to have made their experience more difficult.

The Govender and Moodley families appeared to have experienced a lot of disruption in their family lives as a result of Devon and Ingrid's illnesses. Both families had financial difficulties and also experienced an increase in care related needs. Devon reported that as a result of his HIV infection he became very ill and was unable to work. This resulted in a dramatic reduction in family income and also increasing the care burden on the family. While the Moodley family's financial difficulties predated Ingrid's illness, it did increase their stress burden. Furthermore, Ingrid's HIV also increased the care related burden in the family. It appeared that it had been difficult for the families to cope with their family member's illness.

The families caring for a family member with HIV had to contend with a very variable and possibly prolonged course of illness. While the other two families also had to cope with caring for an ill family member, the course of cancer appeared to be more predictable. The HIV sample had to contend with many health fluctuations in the course of their illness.

During the six years that Devon Govender had been ill, his CD4 cell count had been below 50 (suggesting a severe impairment in his immunological functioning and health) (AIDS Foundation of South Africa, 2000) but he was also very healthy at other times, including

during the two interviews with his family. Ingrid Moodley had difficulties with several severe health problems but was fairly healthy at the time of the interview. Due to the impact of HIV on the immune system, they were both likely to continue experiencing fluctuations in their health due to opportunistic infections from viruses, fungi, bacteria and protozoa (Good, 1984; Tross, 1989). Neither family knew how long their ill family member would live. While the other two families also did not know this, both Harold and Barbara's health appeared to have deteriorated steadily rather than in the fluctuating manner of Devon and Ingrid. The periods of health experienced by Devon and Ingrid may have contributed to the beliefs that were held by both the Govenders and the Moodleys that their ill family members had possibly been cured. It is possible that when their health deteriorated again, their families would have to accept once again that their family member was dying.

In terms of the FAAR model (Baker & Patterson, 1989; McCubbin & Patterson, 1983; Patterson, 1989), these fluctuations in health may have made it more difficult for the families to adjust to the illness of their dying family member. The families caring for a family member with cancer dealt with a progressive illness and would have possibly been able to move roughly in a linear fashion from adjustment, through a crisis period, towards adaptation. While HIV is also a progressive illness, the fluctuations in health appeared to give families hope that their family member was healthy and possibly cured. The family thus possibly moved through several crisis periods as their family members became repeatedly ill and well again. Along with this they possibly also went through the other stages of the FAAR model several times. This may have led to them being repeatedly retraumatised and may have contributed to Charmaine and Devon Govender's difficulties with depression and suicidality.

The families caring for a family member with HIV/AIDS also had to contend with a prolonged course of illness. While Ingrid Moodley was not sure how long she had been infected with HIV and had only been ill for just over a year, Devon Govender had been infected for six years. As has already been discussed, it may take five years after initially becoming infected for an individual to develop a CD4 count low enough to be diagnosed with AIDS (Tross, 1989). After this they may still live a long time. This prolonged period of illness may have increased the financial and care burdens on the families. While cancer can take a long time to develop, the symptomatic phase did not appear to last long for the families in this study. Both Harold Mutara and Ingrid Naran's cancers had metastasised to other parts of their body, suggesting that their cancers were fairly advanced. It was possible that the two subjects with HIV though could still live a long time. This extended the period of disruption in the family (Bor, Miller & Goldman, 1993; Sherr, 1995).

The two families with an HIV positive family member also had to contend with fears regarding transmission. It took two years for Devon to be diagnosed, leaving Charmaine Govender afraid that she too may have been infected. The Moodley family were also concerned about transmission. One of Ingrid's sons possibly moved out of the family house due to fears of infection. Her other son, Thomas, was so afraid of becoming infected that he kept separate bedding from his mother and was concerned about eating food that she had prepared. These concerns are reported to be common elements to the experiences of families caring for a family member with HIV/AIDS (Atkins & Amenta, 1991). While the families caring for a family member with cancer did not have any concerns surrounding infection, the Narans were concerned about the possibility that there was a genetic predisposition in the family to cancer. While this also involved a concern that other family members could become ill, it differed from concerns about infection; genetic predispositions could be transmitted at

conception, but not through body fluids and also not by caring for someone who had the disease. In the Moodley family, concerns about infection may have precipitated the division of the family and also appeared to prevent Thomas from caring for his mother. It appeared that infection concerns made the experience of the HIV families more difficult.

Linked to concerns surrounding transmission were concerns surrounding sexual functioning. Marcus (1999) reported that many people in her focus groups on death and dying experienced sexual difficulties. It is possible that these matters were not raised in the interviews because the whole family were present during interviewing. However, Charmaine Govender was concerned that she could have been infected by Devon, presumably because they had had sex during the period between his infection and his diagnosis. While the cancer families may also have had sexual concerns, these did not involve infection.

It also appeared to be more difficult for the two families with an HIV positive member to access medical treatment and resources. While three of the participant families struggled to obtain a diagnosis, the cancer sample managed to obtain medical treatment with relative ease. This experience differed significantly from the experience of the HIV sample. Ingrid Moodley reported that after she was diagnosed she was discharged from hospital without any referrals for the ongoing management of her illness. The Govender family also had difficulties obtaining medical treatment and only found an HIV clinic at a provincial hospital after a long search for help. To a large extent these difficulties were probably due to the Department of Health's (2002) policy not to supply antiretrovirals at public healthcare facilities. There were thus less treatment options available to individuals with HIV/AIDS. This was in sharp contrast with the cancer sample who could obtain treatment for their ill family member cheaply and easily.

The HIV sample did not appear to have as much social support as the cancer sample. Neither the Govenders nor the Moodleys had been overwhelmed by visitors. The Govenders had struggled to find other families who were living with HIV. Aside from the social support that the families appeared to be receiving from NGOs, they appeared to be relatively isolated. For both families their experience of social support may have been linked to stigma.

Both the Govenders and the Moodleys experienced stigma and prejudice. Ingrid's one son urged her not to let anyone know her diagnosis and another moved away from her, possibly due to fears of infection. Similar reactions were also experienced by many individuals living with HIV in the USA (Tross, 1989). Furthermore, Bor, Miller and Goldman (1993) noted that other people often distanced themselves from people living with HIV/AIDS. These kinds of experiences may have led to these families becoming socially isolated.

The fear of social isolation as a result of others knowing about the HIV also appears to have affected families. Ingrid's son may have been trying to urge her to hide her diagnosis because of a sense of shame and possibly a fear of stigma. Devon and Charmaine Govender also initially tried to hide Devon's diagnosis and instead told people that he had cancer, suggesting that this was a more socially acceptable disease. Marcus (1999) noted that many participants in her study attempted to hide their diagnoses out of shame and a fear of stigma. They sometimes referred to the disease using the names of other diseases.

Research suggests that families caring for an HIV positive family member experience stigma. Marcus (1999) found that many of the participants in her study in Pietermaritzburg reported stigma. It is likely that if the general public demonstrated the high levels of stigma that Herek

and Capitanio (1993) found in the United States, that both the Govender and Moodley families would have been acutely aware of prejudice. Fife and Wright's (2000) study found more experiences of stigma among their HIV/AIDS sample than their cancer sample. They also found high levels of shame among their HIV/AIDS sample about their disease. It is thus not surprising that the HIV families did not experience as much social support as the cancer families.

Both HIV families appeared to be uncomfortable about the association between HIV and promiscuity and tried to distance themselves from this association. Marcus (1999) noted that this was the case in her study as well. It appeared that the families were less troubled by the illness than by its association with promiscuity. The Moodleys distanced themselves from the possibility that Ingrid had become infected by sexual transmission. The Govender family had difficulties accepting that Devon had HIV because he had lived what was described as a moral, non-promiscuous life. It was far more acceptable for the families to believe that their family members infected with HIV were moral victims, and in the case of Ingrid a caring martyr, rather than as agents in contracting the disease. While Devon was a victim, it was quite possible that Ingrid could have become infected through consensual sex. It thus appeared that for the families it was not so much HIV that was difficult to accept, but rather the sexual and moral connotations which it had.

Some experiences may have been due to stigma, a sense of helplessness among medical staff or a combination of both. Charmaine felt that Devon obtained second-rate medical attention when doctors found out that he was HIV positive. While doctors may have been acting out of prejudice, they may also have been demonstrating a sense of helplessness due to the lack of

medical options available to them as a result of the Department of Health's (2002) policy not to provide antiretroviral medication at public healthcare facilities.

However, it also appeared that at least for the Govender family, their involvement in various HIV/AIDS related concerns gave them a sense of meaning and purpose. This appeared to have helped them cope. It is possible that becoming involved in various cancer-related issues could have given the families with a family member with cancer a similar sense of meaning. However, at present HIV/AIDS-related issues appear to be very prominent in the media. The Treatment Action Campaign (2001; 2002a; 2002b) and others have questioned the moral aspects of the government's policies and public's attitudes towards HIV/AIDS. Identifying with and supporting these causes could provide a much broader scope for finding a sense of purpose than becoming involved in cancer-related causes which are not as publicly prominent in South Africa at present. While the above-mentioned factors increased the burden on the families who were caring for a family member with HIV/AIDS, it did appear that HIV/AIDS offered a greater scope for activism and hence a sense of altruism, communality, purpose and meaning.

The families caring for a family member with HIV/AIDS thus appeared to experience disruption in their family lives as a result of the disease. Both appeared to have experienced many financial and care-related stressors. In addition to this they also appeared to have to contend with other factors such as a variable and possibly prolonged course of illness, fears of transmission, difficulties obtaining treatment, little social support and stigma. Despite this, it appeared that HIV/AIDS also offered a scope for activism that appeared to have helped the Govender family to cope. Generally it appeared that it was difficult for the families in this study to cope with HIV/AIDS.

It thus appeared that while each family in this study were confronted with their own distinctive set of circumstances, there were similarities in their experiences. It appeared that the illness brought about a number of stressors in the families, the effect of which was mediated by a number of factors. It also appeared that the burden on the families was borne more intensely by the female family members. It did however, appear that there were differences in the experiences of the families caring for a family member with cancer and families caring for a family member with HIV/AIDS.

All the families had been affected by their family member's illness. The two families caring for a family member with cancer had experienced several stressors, but appeared to be able to access medical treatment and social support easily if they desired it. Both families had been overwhelmed by visitors during the course of their family member's illness. The two families caring for a family member with HIV struggled to obtain medical treatment and also did not appear to have the same level of social support as the other families. It also appeared that they were confronted by several other factors including a more variable and prolonged course of illness, fears regarding transmission and stigma. It appeared that they experienced stigma and also felt a sense of shame regarding the sexual associations of HIV. They appeared to prefer perceiving the ill family member as a moral victim. However, despite the extra burdens facing these families, it did appear that HIV/AIDS presented opportunities for activism which could offer the family opportunities for meaning which could help them cope with the illness.

It appeared that much research could still be done to explore the impact that caring for an ill family member has on a family. The impact that the illness has on specific family members and family dyads could be studied further. For example the impact that the illness has on

children, parents and the marital couple may merit investigation. Much more work could also be done to explore the impact and dimensions of stigma with regards to HIV/AIDS in South Africa. Studies such as those cited by Fife and Wright (2000) and Herek and Capitanio (1993) have contributed much to the knowledge base regarding stigma in the United States of America, but much could still be done to explore stigma in South Africa. More research could also be done to explore social support. Some social support appeared to be more welcome than others. The dimensions of how social support comes to be regarded as welcome and unwelcome could be explored further. The factors that led to the two families caring for a family member with HIV/AIDS being more socially isolated than the other two families could also be studied further. In this regard the perceptions and beliefs regarding HIV/AIDS of the families' circle of friends and themselves could be explored further. It is hoped that this study may lead to further research. The following section explores the limitations of this study.

5.2 Limitations of this study

While this study yielded useful data, it did have several limitations. Data was collected over a limited period of time from a small group of participants. Interviewing whole families may also have imposed limitations on the data. Finally the reliability of the coding was not established. If this study was to be repeated then several measures could be taken to improve the data that was collected as well as to improve the coding of the data.

As both illnesses are chronic, the experiences of the families could fluctuate over time. It is possible that if the families were interviewed at different periods during the course of the illness, the interviews could have yielded data that may have been influenced by their current experiences. This could have been controlled for by interviewing the families at regular intervals over a period of time. It was however, not possible to interview all the families

throughout the course of the illness, as the required time limit for the completion of this research was three years and a person infected with HIV may live longer than a decade. It may nevertheless have been beneficial to conduct several interviews with each family over a period of several months. Single interviews however, proved to yield sufficient preliminary data.

Interviewing the family together also had limitations. Issues that were important to individual family members may not have been raised due to the presence of other family members. An example of this is that the sexual relationship between the marital couple was not raised as an issue of discussion. While other factors such as rapport probably influenced this as well, it is possible that if the marital couple were interviewed on their own, this and other issues may have been raised. Other family members may also have discussed other issues if they had been interviewed alone. Conducting interviews with the family as a whole, as well as with individual family members may have yielded richer data.

Interviewing other significant people outside of the family may also have led to richer data being collected. It is possible that the counsellors from the NGO's that were supporting the families may have been aware of factors that were affecting the families of which they themselves were unaware. While interviewing them alone would not have yielded sufficiently rich data to arrive at an understanding of the 'dasein' (Heidegger, 1982) of the participants, it could have supplemented and enriched the data from the families themselves.

There were also several difficulties associated with using a limited amount of participants from a specific culture. As argued in the methodology section, this did allow for in-depth and explorative research, but it limited generalisability. Furthermore, South Africa has a diverse

population, consisting of many different cultures. It is likely that there may be differences in the family experiences of these cultures. Further research needs to be done to explore the impact that HIV/AIDS has on families from other cultures.

A further difficulty in this research relates to the interpretation process. As a hermeneutic phenomenological study, it is recognized that the interpretation process was subjective (Braine, 1984; Heidegger, 1982; Kruger, 1979; Palmer, 1969; Ricouer, 1981; Welman, 1995) and hence a different researcher may have developed a different thematic framework and also coded the data differently. While the subjective nature of the interpretation process allows for an in-depth understanding of the phenomenon, it is important that this subjective understanding is grounded in the phenomenon itself. While the thematic framework evolved over the course of several readings of the data, and the coding was also reviewed several times, the reliability of these could have been improved by having them reviewed by another coder.

This study could have used a questionnaire-based quantitative methodology as discussed in the methodology section. This would have resulted in more generalisable data. However, as has been argued with regards to many quality of life devices, these devices were developed and normed on North American and European populations which are predominantly homosexual (Joubert, 1991). Work would thus first need to be done in order to assess the validity of these devices for local populations (Sullivan, 1994). The explorative qualitative design adopted for this project appeared to be more appropriate for exploring the impact of HIV/AIDS on South African families. It would however, be important to do further quantitative work in order to develop more generalisable findings.

This research could however, have been improved by implementing several measures. The richness and quality of the data may have been improved by conducting several interviews over a period of time with each family, interviewing individual family members on their own and possibly interviewing the counsellors who were supporting these families. The reliability of the coding process may have been improved with the aid of another person reviewing the coding. Despite this it is felt that the data that was collected proved to yield adequate preliminary data.

5.3 Implications of the findings

This study has several implications for families caring for a family member with a chronic terminal illness. There were several implications regarding social support. Generally social support appeared to be important to the families in this study, but the families experienced ambivalence about social support. Others overwhelmed two of the families with attempts to support them. This may be stressful for other families and they may benefit from support from counsellors when this arises. While the families in this study sometimes struggled to accept help and support from others, they appeared to have found it easier to access support from NGOs. These could be useful as a referral resource for terminally ill clients and their families. As it appeared that the chronic illness often placed an increased burden on the female family members in this study, it is also likely that they would benefit from increased support. Families caring for a family member with a terminal illness such as cancer or HIV/AIDS would possibly be able to cope better if their levels of social support were optimal.

It also appeared that the reported lack of clarity surrounding medical details was a source of stress to the families involved in this study. This would suggest that terminally ill patients and their families could benefit by having their doctors discuss the meaning and implications of

their treatment and symptoms with them. With regards to HIV/AIDS, the Moodley family's lack of understanding surrounding issues such as the transmission of HIV suggests that many other families too could benefit from education surrounding their diseases and how to live with them. This could demystify and decrease families' uncertainty about medical matters.

The families caring for a family member with HIV/AIDS were troubled by difficulties such as stigma and difficulties accessing medical resources. Stigma and shame surrounding HIV/AIDS may still have a significant impact on the lives of many people living with HIV/AIDS, limiting their access to social support and medical treatment. As has been argued, this may increase the burden on these families. It also appears that people living with HIV/AIDS may continue to have difficulties accessing medication for a long time, until government policy and funding changes. It is important that these issues continue to be addressed on a broader social level.

6 Conclusion

It thus appeared that the participants in this study were all deeply affected by the illness of their family member. It appeared that the illness brought about a number of stressors in the families which they responded to according to several unique mediating factors. Stressors facing the family included financial stressors, care-related stressors, role changes, difficulties accessing medical treatment, uncertainty and the psychological responses of family members. The families responded to these according to a variety of mediating factors such as the family's abilities, social support, a variety of meaning factors and stigma.

Despite the common aspects to the experiences of the families in this study, it appeared that there were differences in the impact that cancer and HIV/AIDS had on the families. The

families caring for a family member with cancer appeared to have greater access to social support and medical treatment than the families caring for a family member with HIV/AIDS. Furthermore, it also appeared that the families caring for a family member with HIV/AIDS had several additional burdens to cope with. These included having to cope with a more variable and prolonged course of illness, fears of infection and stigma. These experiences made it more difficult for families caring for a family member with HIV/AIDS to do so. However, it did appear that HIV/AIDS offered opportunities for activism that could help these families to cope. Nevertheless it appeared that while it was difficult for families to care for a family member with cancer or HIV/AIDS, the HIV/AIDS sample had to contend with more stressors than the families with cancer.

- AIDS Foundation of South Africa (2002). The HIV/AIDS virus [Online]. Available: <http://www.aids.org.za/about.htm> [2002, August 13].
- Allen, D. M., Simelela, N. P., & Makubalo, L. (2000). Epidemiology of HIV/AIDS in South Africa. The Southern African Journal of HIV Medicine, 1(1), 9-11.
- Atkins, R., & Amenta, M. O. (1991). Family adaptation to AIDS: A comparative study. In M. O. Amenta (Ed.). AIDS and the Hospice community. (pp. 71 – 83). London: Harrington Park Press.
- Baker, L. C., & Patterson, J. M. (1989). Introduction to family theory. In C. N. Ramsey (Ed.). Family Systems in Medicine. (pp. 57 – 61). New York: Guilford Press
- Beavers, W. R., & Voeller, M. N. (1983). Family models: Comparing and contrasting the Olson Circumplex model with the Beavers systems model. Family Process, 22, 85 – 98.
- Beavers, W. R. (1989). Beavers system model. In C. N. Ramsey (Ed.). Family Systems in Medicine. (pp. 62 – 74). Guilford Press: New York.
- Berard, R. M. F. (2001). Depression and Anxiety in oncology: The psychiatrist's perspective. Journal of Clinical Psychiatry, 62 (supplement 8), 58-61.
- Bor, R., Miller, R., & Goldman, E. (1993). HIV/AIDS and the family: A review of research in the first decade. Journal of Family Therapy. 15, 187-204.

Braine, J. (1984). Anorexia Nervosa: An appraisal in terms of adolescent development with implications for educational intervention. Unpublished Masters Thesis, University of Natal, Pietermaritzburg.

Brittain, D. (2000). The haematology of HIV infection. The Southern African Journal of HIV Medicine, 1(1), 37-38.

Cairns, J. (1978). Cancer: Science and society. San Francisco: W.H. Freeman and Company.

CANSA. (1998). CANSA: Cancer association of Southern Africa [Online]. Available: <http://www.cansa.org.za/information.asp> [2002, February 27].

Cella, D. F., McCain, N. L., Peterman, A. H., Mo, F., & Wolen, D. (1996). Development and validation of the Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) quality of life instrument. Quality of Life Research, 5, 450-463.

Cleary, P. D., Fowler, F. J., Weissman, J., Massagli, M. P., Wilson, I., Seage, G. R., Gatsonis, C., & Epstein, A. (1993). Health-related quality of life in persons with acquired immune deficiency syndrome. Medical Care, 31 (7), 569-580.

Copter, A. E., Ampel, N. M., Hughes, T. E., Gregor, K. J., Dole, C. L., Loons, S. J., Colgan, K., & Wu, A. W. (1996). The use of two measures of health-related quality of life in HIV-infected individuals: A cross-sectional comparison. Quality of Life Research, 5, 281-286.

Coyle, N., Localzo, M., & Bailey, L. (1989) Supportive home care for the advanced cancer patient and family. In. J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: Psychological care of the patient with cancer. (pp.598–606). New York: Oxford University Press.

DeBoer, J. B., Sprangers, M. A. G., Aaronson, N. K., Lange, J. M. A., & Van Dam, F. S. A. M. (1996). A study of the reliability, validity, and responsiveness of the HIV Overview of Problems Evaluation System (HOPES) in assessing the quality of life of patients with AIDS and symptomatic HIV infection. Quality of Life Research, 5, 339-347.

Department of Health. (2000). HIV/AIDS/STD strategic plan for South Africa 2000- 2005 [Online]. Available: <http://www.doh.gov.za/docs/policy-f.html> [2002, August 1].

Department of Health. (2002). Recommendations for the prevention and treatment of opportunistic and HIV related diseases in adults [Online]. Available: <http://doh.gov.za/aids/index.html> [2002, July 8].

Els, C., Boshoff, W., Scott, C., Strydom, W., Joubert, G., & Van Der Ryst, E. (1999). Psychiatric co-morbidity in South African HIV/AIDS patients. South African Medical Journal, 89(9), 992-995.

Evian, C. (1993). Primary AIDS care: A practical guide for primary health care personnel in the clinical and supportive care of people with HIV/AIDS. Johannesburg: Jacana.

- Farber, E. W., & McDaniel, J. S. (2002). Clinical management of psychiatric disorders in patients with HIV disease. Psychiatric Quarterly, 73(1), 5-16.
- Ferrando, S. J., & Wapenyi, K. (2002). Psychopharmacological treatment of patients with HIV and AIDS. Psychiatric Quarterly, 73(1), 33-49.
- Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. Journal of Health and Social Behavior, 41, 50-67.
- Galloway, M. R. (2000). South African AIDS vaccine initiative: Working not waiting. The Southern African Journal of HIV Medicine, 1(1), 39-41.
- GLOBOCON. (2002). GLOBOCAN [Online]. Available: <http://www-dep.iarc.fr/globocan/globocan.html> [2002, March 6].
- Good, R. A. (1984). Immunologic aberrations: The AIDS defect. In K. M. Cahill (Ed.). The AIDS epidemic. (pp. 41–59). London: Hutchinson.
- Heidegger, M. (1982). The basic problems of phenomenology. (A. Hofstadter, Trans.). Bloomington: Indiana University Press. (Original work published 1975).
- Herek, G. M., & Capitanio, J. P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. American Journal of Public Health, 83(4), 574-577.

Holland, J. C. (1989). Clinical course of cancer. In J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: Psychological care of the patient with cancer. (pp. 75 – 100). New York: Oxford University Press.

Holland, J. C. (1989). Radiotherapy. In J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: The psychological care of the patient with cancer (pp. 134-145). New York: Oxford University Press.

Holland, J. C., & Lesko, L. M. (1989). Chemotherapy, endocrine therapy, and immunotherapy. In J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: The psychological care of the patient with cancer (pp. 146-162). New York: Oxford University Press.

Holmes, W. C., & Shea, J. A. (1997). Performance of a new, HIV/AIDS-targeted Quality of Life (HAT-QoL) instrument in asymptomatic seropositive individuals. Quality of Life Research, 6, 561-571.

Holmes, W. C., & Shea, J. A. (1998). A new HIV/AIDS-targeted Quality of Life (HAT-QoL) instrument: Development, Reliability, and validity. Medical Care, 36, 138-154.

Hughes, J. (1987). Cancer and emotion: Psychological preludes and reactions to cancer. Chichester: John Wiley & Sons.

Huysamen, G. K. (1994). Methodology for the social and behavioural sciences. Johannesburg: International Thomson Publishing (Southern Africa) (Pty) Ltd.

- Jacobsen, P., & Holland, J. C. (1989). Psychological reactions to cancer surgery. In J. C. Holland & J. H. Rowland (Eds.), Handbook of psychooncology: The psychological care of the patient with cancer (pp. 117-134). New York: Oxford University Press.
- Jones, R. D. (2001). Depression and anxiety in oncology: The oncologist's perspective. Journal of Clinical Psychiatry, 62 (supplement 8), 52-58.
- Jordaan, J. P. (1982). Cancer: Disease or disaster? Inaugural lecture, University of Natal, Durban.
- Joubert, D. (1991). AIDS and its social context. In A. van Niekerk (Ed.), AIDS in context: A South African perspective (pp. 22 - 36). Lux Verbi: Cape Town.
- Kruger, D. (1979). An introduction to phenomenological psychology. Cape Town: Juta & Co.
- Labovitz, S., & Hagedorn, R. (1981). Introduction to social research (3rd ed.). New York: McGraw-Hill Book Company.
- Lachman, S. J. (1990). The challenge: AIDS in the 1990's - A guide for modern medical practitioners and health care workers (3rd ed.). South Africa: Lennon Limited.
- Lesko, L. M. (1989). Bone marrow transplantation. In J. C. Holland & J. H. Rowland (Eds.), Handbook of psychooncology: The psychological care of the patient with cancer (pp. 163-173). New York: Oxford University Press.

Marcus, T. (1999). Wo! Zaphela izingane: It is destroying the children: Living and dying with AIDS. Unpublished paper for the CINDI (Children In Distress) Network, Pietermaritzburg.

Massie, M. J., & Holland, J. C. (1989). Overview of normal reactions and prevalence of psychiatric disorders. In J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: The psychological care of the patient with cancer (pp. 273-282). New York: Oxford University Press.

Mitchell, P. K., & Peil, M. (1982). Social science research methods: An African handbook. London: Hodder & Stoughton.

McCubbin, H. I., Joy, C. B., Cauble, A. E., Comeau, J. K., Patterson, J. M., & Needle, R. H. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42 (4), 855-871.

McCubbin, H. I., & Patterson, J. M. (1983). Family transitions: Adaptation to stress. In H. I. McCubbin & C. R. Figley (Eds.). Stress and the family: Vol. 1. Coping with normative transitions (pp. 5-25). New York: Brunner/Mazel.

Mead, S. C. W., & Willemsen, H. W. A. (1995). Crisis of the psyche: Psychotherapeutic considerations on AIDS, loss and hope. In L. Sherr (Ed.). Grief and AIDS (pp. 115-127). Chichester: John Wiley & Sons.

Miller, S. (2000). Southern African HIV clinicians' society: Guidelines for antiretroviral therapy in adults. The Southern African Journal of HIV Medicine, 1 (1), 22-27.

National cancer registry [Online]. (2001). Available: <http://www.cansa.co.za/registry.asp> [2001, October 22].

Normile, L. B. (1990). Psychological distress in bereavement: A comparative study of parents of adult children who died of cancer versus AIDS. Dissertation Abstracts International B, 50, 2840.

Olson, D. H., Russell, C. S., & Sprenkle, D. H. (1983). Circumplex model of marital and family systems: Theoretical update. Family Process, 22, 69-83.

Palmer, R. E. (1969). Hermeneutics: Interpretation theory in Schleiermacher, Dilthey, Heidegger, and Gadamar. Evanston: Northwestern University Press.

Parkin, D. M., Pisani, P., & Ferlay, J. (1999). Estimates of the worldwide incidence of 25 major cancers in 1990. International Journal of Cancer, 80 (6), 827-841.

Patterson, J. M. (1989). A family stress model: The family adjustment and adaptation response. In C. N. Ramsey (Ed.). Family systems in medicine (pp. 95-118). New York: Guilford Press.

Peil, M. (1982). Social science research methods: An African handbook. London: Hodder and Stoughton.

- Pillay, A. L. (2001). Psychological symptoms in recently diagnosed cancer patients. South African Journal of Psychology, 31 (1), 14-18.
- Pisani, P., Parkin, D. M., Bray, F., & Ferlay, J. (1999). Estimates of the worldwide mortality from 25 cancers in 1990. International Journal of Cancer, 83 (1), 18-29.
- Rait, D., & Lederberg, M. B. (1989). The family of the cancer patient. In J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: Psychological care of the patient with cancer. (pp. 585 – 597). New York: Oxford University Press.
- Revicki, D. A., Chan, K., & Gevirtz, F. (1998). Discriminant validity of the Medical Outcomes Study cognitive function scale in HIV disease patients. Quality of Life Research, 7, 551-559.
- Ricoeur, R. (1981). Hermeneutics and the human sciences: Essays on language, action and interpretation. Cambridge: Cambridge University Press.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. Burgess (Eds.). Analysing qualitative data. (pp. 75-195). London: Routledge.
- Schaaf, H. S., Cotton, M. F., De Villiers, G. S., & Donald, P. R. (2000). Clinical insights into the interaction of childhood tuberculosis and HIV in the Western Cape. The Southern African journal of HIV medicine, 1 (1), 33-35.

Schlebusch, L. (1990). Applications of clinical health psychology to nephrology. In L.

Schlebusch (Ed.). Clinical health psychology: A behavioural medicine perspective. (pp. 144-160). Halfway House: Southern Book Publishers.

Schlebusch, L. (1999). Psychological recovery from cancer. Cape Town: Maskew, Miller Longman.

Sherr, L. (1995). The experience of grief: Psychological aspects of grief in AIDS and HIV infection. L. Sherr. (Ed.). Grief and AIDS (pp. 1-27). Chichester: John Wiley & Sons Ltd.

Sullivan, M. (1994). Letters to the editors: Cross-cultural validation for Quality of Life. Journal of Clinical Epidemiology, 47 (12), 1465-1466.

Treatment Action Campaign. (2001). Breaking news; 14 December 2001 [Online]. Available: <http://www.tac.org.za/BreakingNews/14December2001.txt> [2002, September 27].

Treatment Action Campaign. (2002a). Summary of resolutions adopted at the TAC NEC meeting – 19/20 January [Online]. Available: http://www.tac.org.za/Documents/Statements/TAC_aims_2002.txt [2002, September 27].

Treatment Action Campaign. (2002b). Mother-to-child transmission prevention (MTCTP) court case victory – 11 March 2002 [Online]. Available: http://www.tac.org.za/Documents/MTCTCourtCase/mtct_short_judgement.txt [2002, September 27].

Tross, S. (1989). Acquired Immunodeficiency Syndrome (AIDS). In J. C. Holland & J. H. Rowland (Eds.). Handbook of psychooncology: Psychological care of the patient with cancer. (pp. 254–270). New York: Oxford University Press.

Tyckoson, D. A. (1985). AIDS (Acquired Immune Deficiency Syndrome). Phoenix: Oryx Press.

Welman, M. (1995). Death and gnosis: Archetypal dream imagery in terminal illness. Unpublished PhD thesis, Rhodes University, Grahamstown.

Williams, R. J., & Stafford, W. B. (1991). Silent casualties: Partners, families, and spouses of persons with AIDS. Journal of counselling and development. 69 (5), (pp. 423 – 427).

Worden, J.W. (1991). Grieving a loss from AIDS. In M. O. Amenta (Ed.). AIDS and the Hospice community (pp. 143-150). Binghampton, New York: Harrington Park Press.

Wu, A. W., Revicki, D. A., Jacobson, D., & Malitz, F. E. (1997). Evidence for reliability, validity and usefulness of the Medical Outcome Study HIV health survey (MOS-HIV). Quality of Life Research, 6, 481-493.

8.1 Appendix A: Consent form 1

This interview is part of a thesis that is part of the academic requirements towards the completion of a Master's degree in clinical psychology at the University of Natal, Pietermaritzburg. It is an investigation into the experiences of people with AIDS or Cancer and the impact that caring for these people has on their families. The identities of participants will be kept confidential.

I.....

Consent to participating in this research project.

Signed:

Date:

Witness:

Date:

8.2 Appendix B: Consent form 2

I.....

Agree to participate in interviews that will be taped and transcribed as part of a research project conducted by Eugene du Plessis. This project forms part of the academic requirements toward the completion of a Master's degree in clinical psychology at the University of Natal, Pietermaritzburg. The identities of participants will be kept confidential and tapes will be erased once they are transcribed.

Signed:

Date:

Witness:

Date:

8.3 Appendix C: Interview guide

Introductory patter

I am a Psychology Masters student from the University of Natal studying how terminal illnesses affect families. Although I will be taping and typing this interview, I will keep your identities confidential. Is this OK?

Family description

Genogram etc..

Discussion of the illness

What is the diagnosis, course, and the family's experience with the illness?

Demands

What demands have been placed on the family: financial, care, losses etc.?

Response

How have the family responded to the illness: Do they share the burden with others?

Meaning

What does the illness mean to the family: Do they believe they can cope/manage?

Thank you

Thank you for your time and help. Please contact (the assisting NGO) for counselling support if you need it.

8.4 Appendix D: Coding themes

1) Stressors

1.1) Financial

Stressors related to financial factors such family income, savings or the provider role.

1.2) Caring related strains

This refers to difficulties involved in caring for the ill family member or which are related to the caring role.

1.3) Role changes

Many stressful role changes occurred in the families. This theme refers to any role changes that occurred in the family.

1.4) Accessibility of medication and treatment

It was sometimes difficult for family members to obtain medication and treatment. This theme examines these difficulties.

1.5) Uncertainty

These are factors which induce a sense of uncertainty in the family. Examples include uncertainties regarding diagnosis and prognosis.

1.6) Psychological responses

Psychological responses to the illness appeared to be both a response and a further stressor to the family. This theme refers to the psychological impact of the illness on family members.

2) Mediating factors

2.1) Family abilities

Abilities that the family possess which either help them cope or which make coping more difficult. This includes the family's coping style, communication style, ability to adapt and cohesion.

2.2) Existential factors

Meaning factors which either give the family a sense of hope or purpose or which give them a sense of hopelessness.

2.3) Social support

Factors related to the family's experience of social and community support.

2.4) Stigma

Factors related to experiences of stigma and prejudice.