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Family Caring in HIV/AIDS: Experiences, Coping, and Mental Health

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COPYRIGHT STATEMENT

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George Palattiyil
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Where the mind is without fear and the head is held high
Where knowledge is free
Where the world has not been broken up into fragments
By narrow domestic walls
Where words come out from the depth of truth
Where tireless striving stretches its arms towards perfection
Where the clear stream of reason has not lost its way
Into the dreary desert sand of dead habit
Where the mind is led forward by thee
Into ever-widening thought and action
Into that heaven of freedom, my Father, let my country awake

Rabindranath Tagore, 1913

I dedicate my work to

My Dad

Who always strove to give me the best in life

ABSTRACT

This study investigated the experiences of family caregivers of persons living with HIV/AIDS in two contexts of development – Kerala and Scotland. Although the study was primarily qualitative in nature, it incorporated some quantitative methodology in order to connect the findings to existing literature on stress, coping, and mental health.

In-depth interviews were conducted with 23 respondents in Kerala and 5 in Scotland. Interview transcripts were analyzed for major themes, using elements of grounded theory. Quantitative measures included the Ways of Coping Questionnaire (Folkman & Lazarus, 1985) and the Self Report Questionnaire (Beusenberg & Orley, 1994). Results were analyzed for differences in coping style and mental health between the settings. Exploratory correlational and regression analyses were also conducted.

The results indicated that caregivers from both contexts experienced significant burdens. The major experiences of the caregivers in Kerala consisted of poverty, stigmatization, discrimination, lack of support networks and adequate healthcare facilities. While the caregivers in Scotland shared some of these experiences at a lesser degree, their dominant experiences centred on caregiving stress, limited support, role stress, difficulty finding and maintaining a job, and lack of recognition of carers' needs. Quantitative findings indicated that carers in Scotland used a wider array of coping strategies and were more likely to rely on problem-focused coping than the Kerala respondents. Although the carers in both settings experienced significant indicators of psychological distress, the level of symptoms was higher for the carers in Kerala. Correlational and regression analyses explored relationships among setting, gender, coping, and mental health problems.

The findings were discussed in terms of the existing literature related to family-caring in HIV/AIDS, coping, and mental health. Synthesis of the findings led to the emergence of three unifying concepts of struggle, commitment and resilience. A model was proposed that explained the relationship among the three unifying concepts.

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CHAPTER 1: INTRODUCTION

Prelude

The first cases of the Acquired Immune Deficiency Syndrome (AIDS) were discovered in the United States in 1981, and now nearly two and a half decades later, it is estimated that well over 20 million lives have been lost, while some 37.8 million people worldwide—increasingly women and young persons—are presently living with the Human Immunodeficiency Virus (HIV; UNAIDS, 2004a).

HIV/AIDS is the "most globalized epidemic in history" (Piot, 2004, p.8), and is described as "univocally the most devastating disease ever faced" (Piot, 2001, p.1), with no region of the world being spared (Annan, 2004). Further, Annan (2004) argues that "the global AIDS epidemic is one of the greatest challenges facing our generation ... an unprecedented threat to human development" (p.7) that poses a danger not only to an entire generation, but to an entire civilization (Annan, 2000).

HIV/AIDS presents a unique global threat especially in the developing world, where 95 percent of HIV-positive people live, and where only 7 percent of those who needed life-saving treatment could obtain it in 2003. This stands in stark contrast to the developed world, where such treatment has become a part of the standard health practice (UNAIDS, 2004a). In the hardest-hit countries, HIV/AIDS is dramatically reducing life expectancy and economic potential, thus increasing the vulnerability of future generations. Moreover, the HIV infection rates continue to climb in many countries, including some of the world's most populous countries such as China, India, Indonesia, and Russia. Cameron (2001) evocatively comments that "if Larry Kramer could term AIDS in America a 'Holocaust' (1994), then the situation elsewhere defies the capacity of language to describe it" (p.2).

India stands face to face with a complex HIV/AIDS epidemic—an estimated 5.1 million people live with HIV/AIDS in India (National AIDS Control Organization, 2004a). Pisani (2002) notes that India, a country with one-and-a-half times the population of Africa put together, has led the rest of the world in new infections. Because of her vast population, even a small rise in the infected population translates into huge figures. According to the latest estimates the population of India stands over a billion—in July 2004 India's population was 1,065,070,607 (Central Intelligence Agency, 2004). Piot (2004) points out that the large, populous country of India is of particular concern because, although the general prevalence is low, it masks serious epidemics already under way. Moreover Pisani (2002) points out that a debate about the true magnitude of the HIV/AIDS epidemic in India continues to rage and that activists within the country claim that the real total is way above the projections of the national government. In contrast, the prevalence of HIV and AIDS in the United Kingdom is significantly lower. As of December 2004, there have been 21,010 diagnoses of AIDS in the United Kingdom (AVERT, 2005b).

In less than quarter of a century HIV/AIDS has had a transformational effect on the world. The virus has moved quickly and silently, weaving itself into the DNA of millions of people, weakening their immune systems, challenging the very fabric of our society (UNAIDS, 2004a).

The HIV/AIDS epidemic has become a focus of political, economic, and social concern around the world. As the realities of the epidemic have become apparent, HIV has become a topic of widespread scientific interest, as well as a focus for a plethora of social service and economic assistance efforts. Yet despite the interest in HIV and its consequences, relatively little attention has been paid to those who bear some of the greatest burdens in caring for HIV-affected persons—the family carers.

Family carers are the cornerstone in the support of people living with HIV/AIDS; they are the invisible heroes in this third decade of HIV/AIDS. Without their contribution, the predicament of many a person living with HIV/AIDS across the world, irrespective of the context of development they live in, would be unimaginable. Grant (2003) suggests that over the centuries, families have been the "bedrock of care" (p.97), providing support for their ailing/disabled family members, and this has been a symbol of their natural love and altruism. While the sentiments remain the same, the stigma and discrimination associated with HIV/AIDS has brought a new and poignant dimension to the aspect of family caring.

Almost universally, relatives and friends provide up to 90 percent of the treatment, care, and support of persons living with HIV/AIDS (UNAIDS, 2004a). According to the National AIDS Control Organization (2003) there are three million carers of family members living with HIV/AIDS in India. The situation appears somewhat different in Scotland, where persons living with HIV and AIDS have access to the National Health Service, the state-sponsored medical care; however, no statistics on the actual proportion of care provided by family members are available. Nonetheless, informal accounts of family carers in Scotland suggest that they too provide a significant degree of care for their HIV/AIDS-affected loved ones.

HIV/AIDS poses a grave threat to families, societies, and economies worldwide. As the HIV epidemic has become a worldwide health concern, it has also become a worldwide family concern. In communities throughout the world, families face the daily hardships associated with HIV and AIDS, including severe illness, loss of income, social stigmatisation, and bereavement. In many cases, family members also provide all or nearly all of the nursing care required by the affected members—care that can consume family resources in time, money, and energy.

The HIV/AIDS epidemic has impinged on the world in a unique way, decimating large populations in many parts of the developing world. In some rural parts of Africa, AIDS is referred to as the “grandmother’s disease” because it is the grandmothers who are the only ones left in the villages to care for their children who become ill and to raise their orphaned grandchildren. Even in industrialized countries where health care is usually provided by formal medical institutions, family and friends still provide a significant level of services to those with HIV/AIDS, including such services as giving medications, managing daily hygiene needs, providing food, and performing household chores.

Despite the importance of their contributions, the work of family carers is virtually invisible. Very little attention has been paid to the phenomenon of family care for HIV/AIDS patients, particularly in the less developed parts of the world, where it is the predominant form of care (Aggleton & Warwick, 1999; World Bank, 1997). Although some industrialized countries have recognized the contributions of family carers and developed formal structures for supporting them, such supports are all but nonexistent in the areas where they are most needed. Little is known or understood about the issues that these family carers face, the resources they draw upon to meet the challenges of family caring, or the effect of that caring on their lives.

This research will focus on the phenomenon of family caring, with the goal of increasing the knowledge about this phenomenon and developing a better understanding of the unique challenges faced by this group, as well as finding possible ways to increase the support and assistance available to family carers. This study is intended as a beginning step towards answering some of the many questions about the experience of family care. The intent is to explore the experience of family caring as it is lived by the carers, to provide a deeper understanding of the challenges they face, the efforts they make to cope with these challenges, and the effect of the experience on their mental health.

For the purposes of this study, the term ‘family’ refers to those people one turns to for help and guidance, and who willingly accept these roles. While the term usually refers to one's biological ‘family of origin’, including parents, siblings, and children, it may include other relatives, such as grandparents, cousins, aunts, and uncles. For many HIV-positive people, family consists of biologically unrelated peers in their community, or ‘reconstituted families’. The *AIDS Caregiver's Handbook* points out that a broad but useful definition of the family is "all those people who decide to go through this experience with their loved one" (Eidson, 1988, p 91). For the purpose of this study the terms *carer*, *family carer* and *caregiver* are used interchangeably, as are the terms *caring* and *caregiving*.

Family Caring in HIV/AIDS: Experiences and Impact

At the outset, common sense would suggest that providing care for someone with a devastating condition such as HIV/AIDS would involve an enormous undertaking for the family carer. The accounts of many carers in this research poignantly reflect the fact that caring for someone who is suffering with a long-term or life-limiting illness, such as HIV/AIDS, is one of the most challenging experiences of their lives, irrespective of the context. Moreover, their accounts suggest that the fundamental importance of their caring continues to go unrecognized, as do its many costs.

The lives of carers are totally engulfed, that is, their lives are dominated and entwined in the lives of the cared-for, where caring becomes the very basis of their lives (Twigg & Atkin, 1995). The psychological and social implications for family carers can be devastating, and seeing the gradual series of losses that HIV/AIDS engenders for the loved one tests their humanity.

Advances in the progress and accessibility of antiretroviral drugs have led to a paradigm shift in much of the industrialized world, where Highly Active Antiretroviral Therapy (HAART) has resulted in a considerable reduction in the incidence of AIDS-morbidity and mortality. AIDS has, in the eyes of many, become a manageable chronic disease (Van Dam & Hutchinson, 2001). With the introduction of new medical treatments, persons with HIV/AIDS live longer. HIV, in many parts of the world has become a chronic illness requiring long-term medical and home-based care. Thus, a considerable amount of responsibility and burden of that care is being thrust on family members who take on the role of carers.

The range of services that carers may be called upon to provide can be quite broad, depending on the nature of the medical problems faced by the family member living with HIV/AIDS. Family carers may be involved in administering medication, cleaning wounds, changing bandages and dressings, preparing special meals, toileting and bathing the ill family member, and providing any other services to enhance the comfort of the affected family member. For most, if not all family carers, these services are provided in addition to the normal household duties that the carer might have. The carers may also take on wage earning and household duties that were once performed by the family member who is ill.

In addition to the burdens associated with nursing the family member with HIV/AIDS, family carers must also deal with circumstances that are often stressful and worrisome. They may be faced with severe economic hardship, due to the loss of income formerly provided by the ill person, particularly if that person was a family breadwinner. They may be dealing with grief as they confront the decline and possible death of the family member with HIV/AIDS. They may also be faced with varying degrees of stigmatisation, which can lead to social ostracism, isolation, and shame. The circumstances of providing family care have the potential to affect carers on many levels—physically, economically, socially, and emotionally. Although these potential stressors can be enumerated, little information exists on the ways that family carers experience these circumstances.

The strains on those caring for people with HIV/ AIDS are potentially enormous. And as the epidemic matures, overwhelming the capacity of the health services in many countries to cope, these strains are being borne increasingly by lay carers within families and communities. These people are a precious resource. The quality of care they provide and their ability to do so over a sustained period depend on the protection of their own well-being and morale. But although this is well recognized in principle, care for the carers is rarely given the priority it deserves, and "burnout" is a serious problem (UNAIDS, 2000).

There is a lack of information on the ways that family carers handle these burdens. Coping, the process of adapting to stressful circumstances, might involve resorting to any of a number of strategies, with varying degrees of success. There is little information about the steps that family carers take to cope with the burdens of family care, yet it is clear that somehow they do manage to survive. Moreover, there is also little understanding of the emotional consequences of their efforts to survive. How do the many losses and burdens affect the emotional well-being and mental health of family carers? Thus this study explores the phenomena of coping and mental health, in an effort to throw light upon these areas and thus bridge the gap in knowledge.

The Impetus of the Study

As a young adult growing up in a small village in Kerala in the 1980's, the researcher encountered the impact of cancer, a terminal illness, on families in his neighbourhood. The dynamics of family caregiving were very pronounced and had an impact on his mind—in particular, the stigma and fear that both the patient and his family experienced. There was an irony and poignancy in the response of the community to the confirmation of the diagnosis: a neighbourhood that offered help and support in normal circumstances ceased to respond in the same way. Their fear was expressed in their stigmatising and alienating approach, rather than a compassionate or supportive response. This experience left an indelible mark on the researcher's psyche despite the fact that fortunately, over the past decades this response to cancer has changed with a greater understanding of the disease.

With the advent of HIV/AIDS in Kerala, the researcher was confronted with the unfolding of a similar scenario, only this time with a truly stigmatising and unknown illness. Around this time, the researcher trained to become a social worker, and he developed a particular interest in the phenomenon of HIV/AIDS, which posed a major challenge to the person living with HIV/AIDS and to their families and communities.

The researcher's involvement in the field of social work exposed him to the many difficult situations that individuals and families faced in their struggle to survive in the face of dehumanising societal structures of poverty, illness, stigma, and discrimination. Later as a Social Work academic in India, he was involved with both researching and supervising students working with persons infected with and affected by HIV/AIDS. The understanding and awareness that emerged from this involvement, led the researcher to question the many field realities that he encountered.

In an attempt to conceptualise and understand the lived experiences of families affected by HIV/AIDS, the researcher decided to explore the phenomenon of family caring in HIV/AIDS for his doctoral dissertation in Scotland. The researcher's experience of the Indian realities and his exposure to the varied social, cultural, and economic conditions pointed to the differences between the two countries in the context of development and HIV/AIDS.

The researcher realised that it would be valuable to examine the impact of HIV/AIDS on family carers in the two contexts, with a view to developing an understanding of how the developmental context of a country impinges on their lives. Further, it seemed particularly powerful to study the experiences of family carers of persons living with HIV/AIDS in Kerala from their *emic* perspective, that is, from the "native viewpoint". Conversely, it would be equally powerful to look at family carers in Scotland from *etic* perspective, which is obtained by looking at another culture as an outsider. Thus, the study aims at deepening the understanding of the experience of family caring in HIV/AIDS by exploring the life experiences, coping and mental health of 28 family carers in Kerala and Scotland.

Rationale

As mentioned earlier, family carers represent an important but little understood resource in the global struggle to cope with HIV/AIDS. They are the front line care providers for most of the world's HIV-affected individuals, yet few research studies are available about their lives. It is important to learn more about these carers, because they represent an important but virtually invisible resource for dealing with the consequences of HIV/AIDS. Their efforts can help lessen the impact of the disease on communities and ease the burden on governmental or other support systems.

The invisible quality of family carers is particularly evident in the case of HIV/AIDS, where the stigmatizing nature of the illness necessitates that many carers bear their burdens alone and shrouded in secrecy. HIV/AIDS bestows a culture of silence which makes the carers endure the physical and mental suffering they experience alone, and this further increases their invisibility. Thus carers suffer silently of depression, anxiety, or of more severe mental disorders because they have not received either physical or emotional support from medical personnel or from their own communities at the required time.

As the HIV epidemic spreads in the developing world, the role of family carers is likely to grow, and the need to support their efforts will likely grow as well. Understanding the unique circumstances that they face will assist efforts to provide support in ways that are meaningful and useful. Moreover, carers as a group remain under-represented in policy decisions made about HIV/AIDS, despite their important role in caring for those who are afflicted with the disease. Therefore this study aims to highlight their concerns, such that they can inform the development of social policies and programmes.

Finally, there exists a paucity of literature relating to family carers in HIV/AIDS. Whereas there are several studies on people with HIV/AIDS and on care, very little formal research has focused on family caregivers. Moreover, no studies have been found that bring together experiences of caregivers, their coping strategies, and the effect on their mental health in either of the settings. Additionally, the uniqueness of this study stems from the fact that it undertakes a cross-cultural exploration, using both qualitative and quantitative methods, from the perspective of the carers themselves. Thus, the present study aims to bridge a significant gap in the body of knowledge.

Contribution to Theory and Practice

The essential contribution of this research to theory and practice is to make family carers more visible. HIV/AIDS presents great challenges, not just to the person living with HIV/AIDS, but also to their family carers who undertake to provide their care. In most cases, carers are family members with little training or expertise and few resources to draw upon as they face the enormous tasks of caring. Their contributions have up to now been virtually invisible to our understanding of the HIV/AIDS epidemic, despite the crucial role that they play in supporting their family member living with HIV/AIDS. While often unrecognized, they continue to act as key resources in the fight against HIV/AIDS. Their efforts can help lessen the impact of the disease on communities and to ease the burden on governmental or other support systems. Accordingly, planning and services for persons living with HIV/AIDS must consider family carers and recognize the roles that they play. Recognition is essential at all levels of HIV/AIDS planning, and is an integral part of HIV/AIDS management.

This research will also contribute to theory by examining the phenomenon of family caring in HIV/AIDS from the perspective of the carers themselves in two differing settings. Moreover, the use of both qualitative and quantitative approaches endeavours to develop a better understanding of the challenges faced by family carers, the strategies they use to cope with these challenges, and the impact that the experiences have on their mental health and general well-being. The qualitative aspect of this study has the potential to generate new theory and new areas for research and to raise new questions that flow out of the reported experiences of family carers. Utilisation of the Grounded theory approach within the methodology lends an exploratory nature to the research, which in turn, aims not only to answer existing questions, but to discover new ones. In addition, the quantitative aspect may lead to insights regarding relationships among some of the quantitative variables under study, and may further develop hypotheses that can be tested and cross-validated with larger samples. Thus, the study has the potential of breaking new grounds and contributing to the understanding of the experiences of family carers of persons living with HIV/AIDS, particularly in the developing context of Kerala.

Finally one of the important goals of this study is to make a contribution to social work practice, by increasing the awareness of the important contributions of family carers. It is important for practitioners who provide services to persons affected by HIV/AIDS to understand the ways that these people receive care and to develop systems that support family carers as much as possible. In order to provide assistance that is maximally effective, social workers need a broader understanding of the challenges and resources of family carers, who stand as important but often unrecognized workers in the global fight against HIV/AIDS. The relevance of this research to social work is further elucidated in the final chapter.

Conclusion

This chapter has served as an introduction to the study, setting the stage by pointing out the importance of family carers and the lack of knowledge about their contributions in the worldwide struggle with HIV/AIDS. The rationale for the study and the potential contributions of this research were also highlighted.

This study has sought to highlight the contributions of family carers of people with HIV/AIDS. It notes their resilience in the face of adversity and validates the commitment and struggle that they display in order to provide the much needed care for their family member living with HIV/AIDS. The voices and experiences presented in this study provide an understanding of the psychosocial, coping, and mental health aspects of family carers of people living with HIV/AIDS. The study aims to weave together the qualitative and the quantitative data strands and braid them together to develop a deeper understanding of the phenomenon of family caring of persons living with HIV/AIDS.

There are nine chapters in this study. Chapter 1 outlines and introduces the research and provides an understanding of family caring against the backdrop of the HIV/AIDS epidemic. It explores the impetus and rationale of this research and touches upon the contribution to theory and practice. Chapter 2 provides a review of the literature and an overview of HIV/AIDS, with an emphasis on the epidemic in India and Scotland. It explores the three key areas that the study examines: experiences of family carers of providing care to a loved one with HIV/AIDS, aspects of coping, and mental health. This chapter highlights that whereas much has been written on HIV/AIDS and on aspects of care, coping, and mental health of persons with HIV/AIDS themselves, little has been written that brings these aspects together and explores them in relation to family carers. Chapter 3 discusses the relationship between HIV/AIDS and development and explores how this epidemic impinges on development in the two contexts being studied. Chapter 4 describes the several methodological considerations of the research. It provides an understanding of the unique aspects of this research, such as, the cross national aspects, the combination of qualitative and quantitative research, and the ethical challenges of researching sensitive subjects.

Chapter 5 explores the socio-demographic profile of the respondents with a view to providing a deeper understanding into the lives of the individual family carers. Chapters 6 and 7 discuss the substantive findings that emerged from the lives of the respondents. While Chapter 6 focuses on the qualitative findings in relation to the experiences of the carers, Chapter 7 discusses the quantitative findings in relation to the aspects of coping and mental health. The qualitative method utilised in Chapter 6 emphasis the powerful nature of the experiences encountered by family carers and uses case vignettes to bring the data to life. Chapter 8 summarises the findings in relation to the existing body of literature. It draws on the qualitative and quantitative findings and discusses the three unifying concepts of struggle, commitment, and resilience that emerged from the research. It presents a model that facilitates an understanding of family care giving in HIV/AIDS. Chapter 9 concludes with the contributions and implications of the study for policy, social work practice, and future research and touches upon the limitations of the study. The study is brought to a close with some remarks on the experience of researching the lives of family carers of HIV-positive persons in Kerala and Scotland.

CHAPTER 2: REVIEW OF THE LITERATURE

Introduction

The first chapter defined family carers of persons living with HIV/AIDS and highlighted the impact of providing care on their lives. It also discussed the impetus of the study, its rationale, and its contribution to theory and practice.

This chapter discusses the varied theoretical and empirical literature that provides a context for this research. The chapter is designed to provide the reader with an understanding of the literature in relation to the three main areas of the study: experiences, coping, and mental health in the context of HIV/AIDS. As mentioned in the previous chapter, there is a paucity of empirical literature in relation to family caring in HIV/AIDS, particularly literature that looks at these three elements, which are being examined together in this study. The utilisation of Grounded Theory necessitated the development of concepts after analysis of the data; hence the literature pertinent to the emerging concepts is discussed in Chapter 8. The literature that informs this chapter is drawn from the varied fields of psychology, psychiatry, human rights, social work, and sociology, and from the works of researchers, advocates, and practitioners in the field of HIV/AIDS.

The chapter is divided into six sections. The first section introduces the focus of the review and briefly sets out the plan for the review of literature. The second section presents an overview of HIV/AIDS pandemic. It goes on to explore the epidemic in the two contexts of the study: Kerala and Scotland. The third section explores the varied aspects of family caring in the context of HIV/AIDS. The next two sections discuss the aspects of coping and mental health in relation to caring for a family member living with HIV/AIDS. The final section provides some concluding remarks and points to the next chapter.

HIV/AIDS: A Brief Overview

In order to understand the complexity and the magnitude of the problems that family carers experience, it is important to understand the nature of the HIV/AIDS pandemic and of HIV/AIDS itself. It is beyond the scope of this paper to discuss HIV/AIDS in depth; however, some relevant information will be provided in order to establish the basic context for the study. Greater detail will be provided concerning the scope and history of HIV/AIDS in India and Scotland.

The HIV/AIDS Pandemic

AIDS was first recognised in 1981 and has since become a major worldwide epidemic. AIDS is caused by the human immunodeficiency virus. AIDS is characterized by the progressive loss of the CD4+ helper/inducer subset of T lymphocytes, leading to severe immuno-suppression and constitutional disease, neurological complications, and opportunistic infections that rarely occur in persons with intact immune function.

In the early 1980's reports from the Centres for Disease Control (CDC) first described AIDS as an acute illness in gay men, which was believed to be generally fatal (CDC, 1981). In 1983 HIV was identified as the cause of AIDS. Since then, more than 20 million people around the world have died of AIDS related illnesses (AVERT, 2005b). As mentioned in the Introduction in chapter one, the most up-to-date global summary of the HIV/AIDS epidemic from December 2004 (UNAIDS, 2004a) states that 39.4 million people are currently living with HIV/AIDS worldwide. Moreover, 4.9 million were newly infected with HIV in 2004, and 3.1 million people died of AIDS in 2004.

Development and the Spread of HIV/AIDS

The global AIDS epidemic has been with us for more than 20 years. This global emergency shows no sign of weakening its grip on human society. No region of the world has been spared. The HIV/AIDS crisis continues to deepen in Africa, while new epidemics continue to grow with an alarming speed in Asia and Eastern Europe (Annan, 2004). Far from levelling off, rates of infection are rising in many countries in Sub-Saharan Africa. In 2003 alone, an estimated 3 million people in the region became newly infected. Countries in Eastern Europe and East Asia are experiencing the fastest growing HIV epidemic across the world. The vast, populous countries of China, India, and Indonesia are of particular concern. Although the overall prevalence is low in these countries, it masks serious epidemics already under way in individual provinces, territories, and states (Piot, 2004).

AVERT (2005c) states that an overwhelming majority of 95 percent of persons living with HIV/AIDS live in the developing world. This proportion is set to grow even further as the infection rates continue to rise in developing countries where poverty, poor health care systems, and limited resources for prevention and care exacerbate the spread of the virus.

The literature on HIV/AIDS often reflects that the AIDS epidemic has disproportionately affected those who were already marginalised in society. The impact of HIV/AIDS generally weighs more heavily on the poor, disadvantaged, and illiterate, against whom the balance may be tilted (de Zalduondo, Msamanga, & Chen, as cited in Akeroyd, 1997; Lindenbaum, 1992). Gay, lesbian, and bisexual individuals have been affected by AIDS in large numbers all over the world. According to Herek (1995) and Lloyd and Kuszelewicz (1995) their sexuality marginalised them, but with the advent of AIDS the effects of marginalization have become even more acute. AIDS also further marginalizes persons who are already socially misfits as a result of their behaviour, for example, injecting drug users and sex workers. It also disproportionately affects persons in relation to their ethnicity or wealth, as seen in the pattern of the AIDS epidemic throughout the world (Amaro, 1993; Catalan et al. 1997; Herek & Green, 1995; Paicheler, 1992; Thomas, 1994).

Further, AIDS disproportionately affects the poorest nations. HIV/AIDS has an inordinate impact on the poorest countries, adversely affecting society at its structure—economically, socially, and politically (Moerkerk, 1992). The spread of HIV disease occurs in zones of urban poverty, poor health care, and social disintegration, and in areas where there are already other social and health problems

(Lindenbaum, 1992). These realities make the problem of AIDS in developing countries very complex (Miller & Rockwell, 1988), and HIV/AIDS is increasingly becoming an issue of development (Altman, 1993).

The impact of HIV epidemic on development can be illustrated by examining the history of the epidemic in India and Scotland, the two countries that are the focus of this cross-national study. These two countries differ greatly in the level of development, and in the pattern of the HIV/AIDS epidemic.

HIV/AIDS in India

HIV was first detected in six sex workers living in Madras in 1986 (Pais, 1996; Ramalingaswami, 1992) which was five years after the disease had first revealed itself in the United States. It was not until the early part of the 1990's that India showed up on any international health indicator as a threatened country (Burns, 1996). At the start of the Indian epidemic the general impression was that the virus had a very low prevalence in the country and would be of little consequence to the health of its citizens (Pais, 1996). For a long time, Indians, irrespective of their class, caste, ethnic, or cultural background, believed that their deep-seated family traditions, social conservatism, and spirituality would protect them from the harms of this global epidemic (McDonald, 1992). They considered themselves to be a sexually conservative society. However, the considerable socio-economic growth that was occurring in India, along with the increase in migration from small villages to urban cities, had begun to challenge traditional values and practices.

Many, especially those in government positions, initially believed that the virus was being brought into the country by foreign tourists and students (Pais, 1996). The government established a plan that would deport any non-Indian citizen who tested HIV-positive (Pais, 1996). As the infection continued to expand however, government officials began to realise that these policies were failing to arrest the spread of the disease, and they were then repealed. Pais (1996) argues that the Indian government chose to turn its head away from the growing number of individuals dying from the disease. It is interesting that it was not very different in the United

States, where also, at the time of the initial outbreak, no one in the government wanted to make an issue of what many believed were social deviants. The high-risk groups in India were similarly stereotyped as deserving their disease because of their promiscuous behaviour.

The transmission of HIV virus in India has occurred mainly through heterosexual sex (often with a sex worker), injecting drug use, and infected blood transfusions. Generally all three areas overlap. Although HIV/AIDS is still mainly concentrated in at-risk populations that include sex workers, injecting drug users, and truck drivers, surveillance data indicate that in some regions the HIV/AIDS pandemic is moving beyond these groups and into the general population. Moreover, it continues to move from urban to rural districts (Kaiser Network, 2003; United States Agency for International Development, 2002) and towards women and young persons. Heffernan (2004) estimates that 22 percent of HIV cases in India are found among housewives with a single partner. The increasing HIV prevalence among women can also be seen in the increase of mother to child transmission of HIV and in paediatric HIV cases (AVERT, 2005d). The principal mode of HIV transmission is through heterosexual sex, and the second most common mode is injecting drug use. Earlier blood transfusion and blood product transfusion were also major sources, but blood safety measures are now in place to prevent such transmission (AVERT, 2005d).

Male migrant workers and female sex workers are the two principal elements in heterosexual transmissions. AVERT (2005d) argues that migration is rather common phenomenon all over India. Migrant workers tend to be highly mobile and often live in unhygienic conditions in urban slums. Long working hours, relative isolation from the family, and geographical mobility may encourage casual sexual relationships and make these individuals vulnerable to HIV/AIDS. Often returning or visiting migrants, many of whom do not know their HIV status, may infect their wives in the home. Women often get drawn into sex work because of poverty, domestic abuse, and or other social circumstances that force them into it.

Truck drivers and their helpers are an important factor in the HIV/AIDS scenario in India. Rao et al. (1999) point out that India has one of the largest road networks in the world, and an estimated 2 to 5 million people work as long distance truck drivers and helpers. Rao et al. argue that the extended periods of time truck drivers spend away from their families place them in close proximity to "high-risk" sexual networks, often resulting in an increased number of sexual encounters. Rao et al. found that 87 percent of the drivers had frequent and indiscriminate change of sexual partners, and only 11 percent used condoms, although their knowledge of HIV/AIDS was fairly adequate. AVERT (2005d) argues that the HIV prevalence patterns in truck drivers tends to mirror the local epidemics.

India is rendered particularly vulnerable to the HIV/AIDS epidemic because of various factors. These include poverty, a large country with diverse socio-economic norms, and very low levels of literacy in parts of India, contributing to perpetuation of myths and misconceptions, huge migrant populations, untreated sexually transmitted infections due to lack of awareness and access to health care, and vulnerability of women to HIV/AIDS because of gender inequality (UNAIDS, 2004a).

In India, government statistics put the number of people living with HIV/AIDS at up to 4.58 million in 2002 (NACO, 2004a). India accounts for almost 10 percent of the 40 million persons living with HIV/AIDS globally—and over 60 percent of the 7.4 million persons living with HIV/AIDS in the Asia and Pacific Region (UNAIDS, 2004b). These statistics suggest that India is on the brink of one of the largest public health challenges in her history. In a country of over one billion persons, between 3.82 million and 4.58 million persons (between the ages of 15 and 49 years) are living with the virus. Although these figures are far less than 1 percent of the country's population and far less than the figures in parts of Africa, India still has the second highest number of persons living with HIV/AIDS in the world, after South Africa. Moreover, Human Rights Watch (2004) points out that although by official counts South Africa has the largest number of people living with HIV/AIDS of any country in the world, many experts consider the Indian figure to be a significant underestimate. The United States National Intelligence Council (2002) estimated that there were between five and eight million people in India living with HIV/AIDS in 2002, and projected that the number would increase to 20 to 25 million by 2010.

HIV/AIDS in Scotland

The AIDS epidemic in Europe and the United States seems to have emerged in waves. The first wave included gay men, followed by the second of injecting drug users, where the ratio of HIV infected men to women was three to one. The third wave of the epidemic appears to be cases resulting from heterosexual transmission, which involves women more than men (Bury, 1992). In the United Kingdom, the majority of adults with AIDS up until the end of 1991 were men. Women only contributed 5 percent. In Scotland the figures were higher at 12 percent. Compared to the UK as a whole, the major mode of transmission in Scotland has been injecting drug use. Scotland in the beginning of the epidemic seemed to have only a few cases in gay men. There was no evidence of an indigenous sexual spread until 1983.

According to Hepburn (1992) more than half those infected with HIV in Scotland acquired it through injecting drugs. Hepburn approximates that a third of this group are women. She asserts that there is also a rising number of people infected heterosexually, of whom two-thirds are women. Morton and Johnson (1996) give more recent, yet strikingly similar statistics. They argue that in Scotland, the epidemic is now predominantly a heterosexual one, with large number of drug users as the main affected group.

The cumulative total of known HIV-positive individuals in Scotland as of September 2004 is 4128; of these 3044 (74%) are male and 1084 (26%) are female. According to the most recent figures on new HIV infections, the 2004 total to date now stands at 274 cases. During July-September 2004, 105 diagnoses of HIV were reported to the Scottish Centre for Infection and Environmental Health (SCIEH), the highest quarterly total on record (SCIEH, 2004). Of the 105 recently reported HIV-positive individuals, 72 (69%) are male, and 69 (66%) are aged between 25 and 44 years. For the United Kingdom as a whole, 66,554 cases of HIV infection and 20,778 AIDS cases had been reported by 30 September 2004 (SCIEH, 2004). Moss (2004) argues that Britain is in the grip of a serious HIV epidemic, as the number of persons living with HIV/AIDS continues to rise.

The statistics for both India and Scotland suggest that HIV/AIDS presents a significant challenge in both countries, as larger and larger numbers of people become infected and debilitated by HIV/AIDS. The challenge of dealing with this reality can be felt at many levels within a society, but particularly at the family level, where there is an intimate connection between the HIV/AIDS-affected person and others. The next section focuses on the impact of this challenge at the family level.

HIV/AIDS and Family Caring

Families play a socializing, protecting, and sustaining role as a major institution in society. Changes that affect one family member may have an impact on other family members, who are intimately connected to the affected person. Profound changes in the life of a family member can also have an impact on the very structure of the family itself. Thus the advent of HIV/AIDS, an illness that can severely debilitate a family member and reduce their ability to fulfil family roles, affects the family in many different ways. From the beginning of the epidemic, it has been observed that HIV and AIDS carry unique psychological and social implications on the affected individual and their family (Kelly & Lawrence, 1988). To develop a deeper understanding of the effect of HIV/AIDS on family caring, it is important to understand the changing concept of family and the change that the notion of a family has undergone.

Family and Care in the Context of HIV/AIDS

The family is the primary unit in a society. It serves the needs of reproduction, child rearing, socialization, protection, and provides nutritional and health care needs of its members. The family is also a major institution of preserving social values, protecting expectations and roles, providing emotional, psychological, spiritual, and material support to members, and strengthening social stability through intergenerational authority and control. Reidy (1997) points out that when young persons with HIV/AIDS require care, they may turn to a member or members of their nuclear family; or through ties of commitment turn to other “family” members, such as a partner, lover, or friend. Harque (1992) and Raveis and Seigel (1991) argue that the family carer is the cornerstone of society's response to HIV/AIDS.

In recent times, however, the concept of family has undergone considerable change. More people live in non-traditional family settings. HIV/AIDS has accelerated this change with its impact upon kinship, housing, and child custody. The structure of families range in form from couples in close, childless relationships through extended family networks that include third degree relatives. The family of an individual can be considered to include the family of origin, the individual’s spouse or partner, and related offspring, as well as their children. Non-coupled individuals may also consider their close friends as family support. An all-encompassing definition of family is therefore probably not possible. The legal definition, too, seems to be insufficient within the reality of HIV/AIDS, as sometimes the carer is outside the traditional nuclear family unit. Therefore Reidy, Taggart, and Asselin (1991), Bor and Elford (1994), and Levine (1994) opine that family should be defined within the parameters of mutual obligation based on affection and devotion, rather than on law. Chilman, Cox, and Nunnally (1988) suggest that families can be seen as small open systems, deeply affected by their internal interpersonal dynamics and by the many aspects of the external environment with which they interact. They aver that from the internal dynamics perspective, everything that happens to one member of the family affects all members.

Family may thus need to be defined in its broadest possible context. Nord (1996) suggests two definitions of family: traditional family systems may be thought of in terms of families of origin, defined through relatives, connected by blood, marriage or adoption; while non-traditional families are families of choice. The latter refers specifically to the network of friends that gay and lesbian people can create to serve in similar functional ways as families of origin when families of origin may reject the gay or lesbian child, and/or the person with HIV/AIDS.

Reidy (1997) notes that in most cultures, the primary source of care at the time of an illness is the family. Usually one person, by virtue of habit, circumstance, or choice, becomes the carer. When an individual member of the family receives a positive HIV diagnosis and shares the information with one or more in the family, the overall ramifications resulting from the disclosure of the diagnosis are numerous and could be agonizing. In many situations, families are the main source of care and support for HIV-infected persons and those with HIV-related disease. This is particularly true in developing countries, where more professional and institutionalised forms of care may not be available to broad segments of the population.

Traditionally family carers are the parents, spouses, and children of people with terminal illnesses. These family members still provide care in many cases involving HIV/AIDS. However, in the case of gay men, it is more often the partners and friends who provide care. Because HIV care involves more diverse social networks, many HIV-positive individuals have redefined family boundaries to include lovers, friends, and other "chosen kin" (Carlisle, 2000; Irving & Bor, 1995). HIV/AIDS has also challenged traditional gender-based attitudes, and men have increasingly taken on the physical care of sick partners and family members (Folkman, Chesney, & Christopher-Richards, 1994).

In this study the term "care" refers to the full range of activities undertaken by family carers in the home, which include psychosocial and emotional support, practical care such as cooking, cleaning, feeding, helping with toilet needs, etc., and the administration of remedies and treatments. Care also includes the more subtle elements such as love and "healing". Family care is thus a broadly defined set of services provided to the HIV/AIDS-affected person by any of a number of individuals who fulfil the broadly defined concept of "family".

Roles and Tasks of the Family Carers

Reviews of the literature on family care (Flaskerud & Ungarski, 1992; Mansour, as cited in Reidy, 1997; McCann & Wadsworth, 1992; Speigel & Meyers, 1991) point out that the role of the carers includes such tasks as emotional support, financial assistance, direct physical care, help with medication, assistance with daily activities, liaising with health and community services, sharing of living accommodation, and social and recreational tasks. The context in which these tasks arise can be at home as well as in the hospice or hospital. These tasks require time, energy, money, and a possible redefinition of family roles (Meyers & Weitzman, 1991).

Early on in the epidemic studies found that for every AIDS patient, an average of eight family members, relationship partners, and significant others were also directly affected by the patient's disease (Walker, 1987). Often these are the individuals who care for the person with AIDS before or after hospitalization. These family caregivers perform a variety of roles that help people with HIV/AIDS adhere to treatment regimens, avoid unnecessary hospital admissions, reduce reliance on formal caregivers, remain at home longer, and maintain quality of life.

Reidy et al. (1991) note that while these tasks may be shared among the family members, there is generally a tendency for the tasks to become the responsibility of one designated carer. Bharat (1996) suggests that the burden of care is usually borne by the women in most families. When family members fall ill, it is women who provide the nursing care and in the case of illness of the breadwinner, it is women who usually take over as providers of basic needs for themselves and other family members. Such women may face the fear of the death of their husband, the fear of becoming infected and feeling helpless, mental stress over the physical and psychological burden of care, and a sense of despondency and failure about the future (Bor, Miller, & Goldman, 1993). The impact of HIV/AIDS on women carers can be devastating, because it affects women not only as carers and as individuals who are infected, but also in their multiple roles in the family and community as mothers, wives, caregivers, educators and providers. Often the woman's role of carer is replaced by being cared for as she develops symptoms herself (Miller & Goldman, 1993; Shaw, 1992).

When there is a sick or dying person in the house, someone quite literally has to care, whether out of love, duty, or simply a lack of options. Indeed, research has indicated that in nearly 90 percent of illnesses, care is provided in the home (World Health Organization, 2000). Although the role that men and boys are playing as providers of care in the context of the HIV/AIDS epidemic has been poorly documented and inadequately understood, it is generally recognized that women and girls are the principal caregivers in the vast majority of homes. Women and girls bear the greatest degree of responsibility for the psychosocial and physical care of family and community members—a responsibility with substantially greater weight in homes affected by HIV and AIDS. It has also been observed that in carrying out this largely unremunerated care work, women and girls are often forced to leave paid jobs, schooling, and other opportunities, and that this care work displaces other health producing activities in the household and community (e.g. Steinberg, Johnson, Schierhout, & Ndegwa, 2002).

Bharat (1996) found that even in instances where there was anger towards the person with HIV, there was no denial of care. The cared-for person was seen as a responsibility and given basic support in terms of physical care, food, and medical treatment. Another task that family carers often assume is acting as a link between the HIV/AIDS affected person and the health care system. Saengtienchai and Knodel (2001), in their study of parental caregivers for AIDS affected patients in Thailand, found that carers often communicate with health care providers and advocate for the ill family member. These tasks can be very time consuming and demanding.

Stages of Caregiving

The type of care required by the HIV/AIDS-affected person tends to change depending on the stage of infection. The practical tasks performed by the carers begin to increase as the HIV affected person becomes increasingly incapacitated. As the type of care becomes more demanding, so does the burden on the family. The time and energy required and the degree of emotional involvement become greater and tend to draw the family away from other normal activities and responsibilities.

The emotional demands of caregiving also change with the progression of the illness. At diagnosis the carer deals with the pain and agony of acceptance and disclosure.

During periods of latency, feelings of hope and uncertainty begin to dominate. At the symptomatic stage, conflict between living life and the caregiving role dominate. In the terminal stages, carers focus on providing comfort and relief from pain and management of extreme symptoms (Reidy, 1997).

Miller (1994) describes four clearly defined developmental stages that carers experience through the progression of illness. These stages can be experienced as different challenges or developmental tasks that carers face in adapting to their role as carers. The stages do not occur in a set order – rather, they may occur together or recur during the course of their caregiving relationship. The first stage is described as the surviving stage. It consists of the activities that the carers do in order to get by and to keep on functioning in the face of many varied changes. The next stage is described as one of searching. This stage consists of the carers beginning to take action and striving to develop a sense of control over their life situation and their emotions. It often involves questioning why the affected person became unwell. It could also involve a search for information and possible interventions for the illness or condition. This stage is followed by the stage of settling. During this period the carer experiences relative calm and a greater sense of control and balance. The final stage is described as one of separating. This stage consists of 'letting go'. During this period the carer begins to relinquish his or her role as carer and allows the affected family member to attain a greater level of independence.

The four stages proposed by Miller (1994) are described as part of a normal process of adaptation. They are useful, as they provide insights that help in understanding the emotions experienced by carers as they adapt to the role of caregiving. However, it is possible that these stages may not fully capture some of the very unique aspects of caring in the case of HIV and AIDS that brings both a special set of circumstances and challenges for the carer as portrayed by the carers in the present study. In the next section, the challenges brought by HIV/AIDS will be discussed in more detail.

The Impact of HIV/AIDS on Family Life

The diagnosis of a family member with HIV/AIDS has significant implications for the entire family. Not only does HIV/AIDS challenge the structures of communities and health services, but it also puts a considerable burden on family caregivers (Enhancing Care Initiative, 2002). This burden can be manifested in many aspects of family functioning. The impact of HIV/AIDS for family carers can include physical, emotional, social, and economic aspects of family life, as well as family relationships. In this section, the impact of HIV/AIDS in each of these areas will be explored.

The physical impact of HIV/AIDS on the family reflects the many additional tasks that come with caring for a severely ill person. Whenever there is a household crisis, such as an illness, the amount of time and energy required to carry out unpaid care work increases exponentially. Depending on the nature of the crisis or illness, the duration of this increased workload can be either short or long-term. HIV/AIDS is a chronic, long-term illness; it is thus classified as a "long-wave disaster" (Barnett & Blaikie, 1992). Family carers may face months or years of additional work as they try to care for the HIV/AIDS-affected person in addition to their normal household duties.

Akintola (2003) examined the physical and psychosocial consequences of providing care for people living with HIV and AIDS, and noted that physical consequences include sudden and recurring head and body aches, as well as fatigue and muscle strain from lifting patients and other chores associated with care-giving. At the same time, caregivers in this study tended to downplay these physical impacts and delayed seeking health care, prioritizing instead the needs of the person for whom they were caring; Hong et al, (2004) also reported similar findings.

The emotional impact of HIV/AIDS on the family can be extremely complicated. HIV/AIDS is an emotionally loaded topic, with its implications of forbidden sexual behaviour and/or drug use, as well as its very severe threat to the survival of the infected person. Thus the emotional impact of caring for a family member who is infected can be characterized by a number of conflicting feelings, such as grief, shame, anger, confusion, blame, and fear, as well as love and loyalty to the infected person.

Reidy and Taggart (as cited in Reidy, 1997) enumerated six principal determinants of the impact of caregiving: the level of dependency of the cared-for; the previous emotional and communication pattern between the carer and the cared-for; the carer's state of physical health; the fatigue experienced in caring; the presence or absence of social support and aid; and finally the conflict between other roles and the role of caregiving.

Family reactions to HIV infection often vary with the nature of the transmission. Issues within families where the affected person has acquired the infection through transfusion of blood products will differ from those where they are homosexual, or a drug user, or where the infection is acquired heterosexually. All have distinct consequences which are patterned on the existing structure of the family. It is not uncommon for gay men to be more distant from their families, both geographically and emotionally, than their heterosexual counterparts, because of the difficulties many parents and siblings encounter in coming to terms with the sexual orientation of their son or brother. On occasions, parents learn of the sexual orientation of their son at the same time as the news that he has HIV infection or is dying of AIDS (King, 1993), thus adding one more difficult element to a situation that is already fraught with conflicting emotions.

Uncertainty about life, illness, and death is probably the most difficult emotional aspects of HIV/AIDS to manage (Barter, Barton, & Gazzard, 1993; Berer & Ray, 1993; Firn, 1996; Miller, 1987; Pierret, 1992). These issues may also become acute as a patient's health deteriorates dramatically. Akintola (2004) reported that carers described feelings of despair and impotence as the death of the cared-for person became imminent (Akintola, 2004). Adjusting to disease progression can be especially difficult for caregivers who have already experienced multiple losses and the attenuation of social support networks (Turner et al, 1994).

These feelings could be compounded for those caregivers who are, or who suspect they are, also living with HIV, as they observe and cope with the severe, sometimes horrific symptoms of AIDS anticipating as they must their own eventual illness and death. Some caregivers continue to be worried by fears of contracting HIV even when they know there is little basis for concern (Wight et al, 1998), perhaps because so many aspects of the illness are mysterious and horrific.

The social climate in which the carer lives can have a great impact on the caregiving experience. The level of general knowledge about HIV and AIDS, as well as cultural beliefs and practices regarding this illness, can greatly influence the level of support and acceptance experienced by carers as they go about the tasks of caring.

Kegeles et al, (1989) suggest that in societies with cultural systems that play a deeper importance on individualism, HIV/AIDS tends to be perceived as the result of personal irresponsibility, and thus the individual is blamed for getting HIV. Warwick et al (1998) point out that in societies where the cultural system gives greater importance to collectivism, HIV/AIDS may be seen as bringing shame on the family and community. As Parker and Aggleton (2002) note, the type of cultural systems and where they fit "along the continuum of individualism and collectivism, will therefore influence the ways in which communities respond to HIV/AIDS and the ways in which stigma and discrimination are manifested" (p.7).

Almost everywhere, the extra burdens of care and support are borne by women, who may experience limited power and authority in traditional societies. These women may have little or no recourse when they need assistance in dealing with the enormous burdens that they face. For the vast majority of AIDS-affected families, the caregivers are not linked to or supported by any formal HIV/AIDS care programme. The implications for these women's health and well-being can be enormous (Akintola, 2003), not least when those providing care are themselves living with HIV.

One of the major obstacles to support for the carers is the stigma associated with HIV/AIDS. Community and/or family rejection of HIV-positive persons often extends to the relatives and friends who provide care (Armstrong, 2000; Wilder, 2000). Rather than face this stigmatization, some caregivers try to conceal their caregiving activities by withdrawing from social relationships. Those who do acknowledge their caregiving status may find it difficult to obtain support from familial or social networks (Mullan, 1998; Turner et al., 1994).

Stigma is "a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons" (Alonzo & Reynolds, 1995, p. 304). Pervasive stigma has surrounded the HIV/AIDS epidemic since its inception and has been accompanied by discrimination, thus affecting access to support and care (Busza, 1999).

Goldin (1994) avers that sexually transmitted diseases have always been instilled with stigma because of their association with deviant/immoral behaviours. UNICEF (2001) argues that no other disease increases human suffering to the extent that HIV and AIDS do, because, it threatens basic human rights and affects human dignity through blame, stigma and discrimination.

Parker and Aggleton (2002) found that HIV/AIDS-related stigma often extended to families, neighbours and friends of persons living with HIV/AIDS (PLWHA). This secondary stigma and discrimination plays a crucial role in both creating and reinforcing social isolation of those affected by the epidemic. Additionally, these acute levels of exclusion weaken social ties and traditional support mechanisms, thereby further isolating families (Help Age International/International HIV/AIDS Alliance 2003).

International Centre for Research on Women (2002) notes that HIV-related stigma is highly complex, dynamic, and deeply ingrained, and it co-exists with care and support of people living with HIV/AIDS. Ignorance or lack of knowledge and fear of HIV contributes to stigma resulting in discrimination. Therefore information and awareness about HIV/AIDS is essential to dispel stigma. As UNAIDS (2003) has noted,

> *Stigma and discrimination both stymie efforts to control the global epidemic and create an ideal climate for further growth. Together, they constitute one of the greatest barriers to preventing further infections, providing adequate care, support and treatment, and alleviating the epidemic's impact (p. 31).*

Those in their prime economically-active years are most likely to acquire HIV infection, and this has a profound impact on the ability of households to maintain viability. The impact of the disease on a household's functioning may build incrementally, and the burden of household work will increase accordingly. As Steinberg et al. (2002 p. i) put it: "in already poor households, HIV/AIDS is the tipping point from poverty into destitution".

In countries with little or no welfare system, orphaned children who are not accepted into extended family networks may become homeless and add to the already growing numbers of street children, who are so vulnerable to physical and mental exploitation, with consequent psychological problems and substance abuse. Older members of extended families, such as grandparents, may be called upon to support their surviving grandchildren while still grieving the loss of their children and facing increasing economic hardship.

As HIV/AIDS undermines the physical and economic resources of the family, it also tears at the relationships and structures that compose the family itself. Healthy members of the family are often forced to assume the roles once filled by the HIV/AIDS-affected person, and this can pose significant relationship dilemmas for family members. This issue can be particularly confusing when women are forced into breadwinning and other roles that were formerly held by their husbands. At the same time, their roles as providers of nurturing and health care may be expanded, leading to exhaustion.

Clearly, being producers of household health (Berman et al., 1994) is a vital social role played by women in many countries, and women do experience improved self-esteem and approval by society for their care-providing skills. However the material and psychological demands placed on them in the context of the HIV epidemic differ dramatically from those required under normal, or pre-epidemic, circumstances. While many women embrace their care-giving roles, they are increasingly being expected to perform these roles under conditions of ever increasing poverty and constraint.

The general level of ignorance about HIV and the risk of infection can place additional pressure on family relationships. An early study by Kelly and Lawrence (1988) found significant reductions in the frequency and closeness of interaction between family members and AIDS patients after their diagnosis. However, the same study found that when the family members became knowledgeable about the lack of transmission risk to household contacts who are not sexual partners of AIDS patients, normal personal interaction patterns were maintained. In a setting where knowledge and understanding of the risk of HIV infection are limited, the conflicting pressures on the carers can be particularly acute, as they cope with fear of their own infection while trying to fulfill the burdens of caring.

Gender and stigma can also interact in painful ways in the care of people living with HIV/AIDS. Although it is not always the case, often when a woman's husband dies of AIDS and she herself becomes ill, the husband's family (who may blame her for "bringing" the illness) will send her back to her natal home to be cared for and to die. This may have important repercussions for her: her fate will often depend on whether or not she managed to maintain close relations with her own kin, and whether they are in a position to take on one or maybe more additional dependent household members. In addition, many of these women will lose access to any inheritance they may have had rights to, and many have their children taken away from them (Food & Agriculture Organization, 2002; 2003,).

The disruption of family roles and relationships also extends to children of the HIV-affected person, who may themselves be infected. There may be particular problems for the well siblings of affected children. Parents may shield the knowledge from them, as they watch their brother or sister inexplicably grow weaker. Children who are aware of the basis of illness in their brother or sister may realise that they are also losing one or both parents, and may fear for their own health. Behavioural and emotional disturbance in the well sibling is possible, and has already been shown to occur in families where children suffer from other chronic medical complaints (King, 1993). The degree of disturbance, however, seems to depend on the level of overall support that is provided to the family from professional and other sources.

At the same time that family relationships and support may be compromised by social stigma and fear, the need for family support may be particularly acute. Although the evidence is scant and somewhat contradictory, close family relationships may actually enhance the physical effects of treatment. At least one study undertaken in Switzerland set out to assess the relationship between stable partnership and clinical outcome in people living with HIV who were receiving HAART (Young et al., 2004). This study found that those patients taking HAART who were in a stable partnership experienced a slower rate of progression to AIDS or death. Family carers, who provide so much of the care afforded to HIV-infected persons around the world, can thus be seen as a key element of treatment, even when more effective medical therapies are available.

The above paragraphs have provided an overview of the multifaceted impact of HIV/AIDS on families and on family carers. It can be seen that the advent of HIV/AIDS in a family can bring about changes in many of the most important aspects of family life and can change the very relationships that make up the family. In the next section, these changes will be examined in relation to the concept of stress.

Family Caring as a Source of Stress

An undercurrent in much of the literature on the family impact of HIV/AIDS is the concept of stress, which seems to fit very well with many of the experiences that families encounter when a member becomes ill with HIV/AIDS. Stress can be defined as a circumstance in which the person experiences events that pose a threat to well-being and place demands upon the person's resources (Lazarus & Folkman, 1984), and certainly HIV/AIDS infection of a family member is such a circumstance.

Carers and their families experience threats to their economic, emotional, and social well-being, as well as recurrent crisis and disruption of family routines (Levine, 1994; Lloyd, 1988; McGrath et al., 1993). Caring for a HIV-affected person also taxes the carer's resources in multiple ways. The sheer physical demands alone contribute to stress, as carers are often called upon to be available 24 hours a day.

Much of the emotional stress experienced by carers lies in the fact that they are dealing with an incurable condition that kills largely young people, causes terrible suffering, and is heavily stigmatized. Because HIV is most prevalent among people under age 40, the caregivers also tend to be relatively young. The non-normative experience of caring for someone with a terminal illness can be a major source of stress for these young adults (Turner et al., 1994). For people of all ages, HIV/AIDS caregiving creates the physical and emotional strain of dealing with an unpredictable and currently incurable disease (Folkman et al., 1994).

Pearlin et al., (1997) discuss the phenomenon of *stress proliferation* in HIV/AIDS caregivers. They note that the primary stresses of caring for an ill family member often lead to secondary stresses that are actually the consequences of the primary stresses. For example, a carer may encounter financial stresses because he or she has assumed the time-consuming tasks of caring and cannot hold down a job.

The timing and pattern of caregiving can also be a factor in producing stress. Brown (1993) and Gaynor (1990) noted that prolonged caregiving can enter either a plateau stage or a course of deterioration of the illness. A "roller-coaster" evolution of the illness produces a cumulatively negative emotional effect on the carer. O'Neill and McKinney (2003) suggest that as treatment options have expanded, so have the stresses experienced by caregivers. The prolongation of the disease course, uncertainty about overall prognosis, and a roller coaster pattern of repeated exacerbations and remissions in later stages of HIV disease have intensified the emotional and physical demands of caregiving. Many of these caregivers face the added burdens of poverty, inadequate housing, and lack of knowledge about available resources. Some are themselves HIV-positive. These developments underscore the importance of recognizing and meeting the needs of HIV/AIDS caregivers over the long term—both for their benefit and for the well-being of people in their care.

Caring affects family life, especially as disease progresses. Someone may need to give up work in order to look after the infected person, and this may result in a decline in family income and living standards and perhaps feelings of resentment, towards the cause—the patient. Bharat (1996) found that the most direct impact was felt through loss of income or reduced pay packet in lower income households where the infected person was the main earner. This resulted in tremendous stresses and tensions within the families. Carers experienced swings in moods. They were caught between the hope of finding a new source of income and despair (Bharat, 1996).

HIV/AIDS, like any other chronic or terminal illness, imposes stress that could have long term disruptive effects on the family unit, and may stimulate the family to reorganise its structure or to increase the cohesion of its members (Durham & Cohen, 1987; Flaskerud & Ungarski, 1992). Caregiving affects family roles and decision making process, which may disrupt other areas of life (financial, career, social etc.) which inevitably increases the stress on the carer (Reidy, 1997). Some authors aver (Reidy, 1997; Cowles & Rodgers, 1991; Ross & Rosser, 1988; Speigel & Meyers, 1991) that when hope begins to erode and gets replaced by a sense of powerlessness in the carer, a feeling of uncertainty is experienced. They suggest that the carer generally shares in the HIV-positive person's anxiety, sadness, guilt, fear, and sense of loss. This, they suggest leads to anger, anxiety, and strain on the family relationships. Brown and Powell-Cope (1991) also found that uncertainty about being able to predict the future and difficult decision-making about life and death created a deep sense of distress among the carers.

One element that significantly adds to the stress that families experience is the high level of stigma attached to HIV and AIDS. The families caring for a member with HIV/AIDS often care greatly about the opinions and comments of their relatives and neighbours and almost everywhere social stigma is attached to HIV infection and

AIDS. Goffman (as cited in Aggleton, 2000) defined stigma as the situation of the individual who is disqualified from full social acceptance. Social stigma and social attitudes are closely linked. Because of imagined or actual social pressure, the family may deny or avoid the subject of the infection or illness. The "conspiracy of silence" imposes a strain on the household; those who care for the patient conceal their emotions, and thus give an impression of indifference to the patient. Perhaps this theme more than any other underpins many of the mental health problems inherent to HIV infection.

The social disruptions that follow the presence of a person with HIV/AIDS in the families cannot be overemphasized. Owing to the stigma associated with HIV/AIDS, families may be isolated and looked down upon by friends, relatives or neighbours. The interpersonal relationships and inter-family relationships can be affected to a large extent, thereby depriving the families of the emotional, material and other support they require to cope with the problems. Avoidant reactions of others can heighten distress and leave the family carers feeling shunned, vulnerable, and isolated from the very persons who had previously been dependable sources of support.

Carers themselves often experience the social stigma that is experienced by those whom they care for. This may be related to fears of infection or to beliefs about the causes of HIV/AIDS. Stigmatisation, coupled with financial, emotional, and physical pressures all generate stress which affects the physical and mental health of the carers (Pearlin et al., 1988). Rose and Clark-Alexander (1998) studied family carers of children with HIV/AIDS and noted that fear of stigmatisation and rejection often contributed to a sense of isolation of parent carers. They were less able to turn to their usual sources of support because of negative reactions, and thus had to face many of their burdens alone.

Carmack (1992) points out the rather harsh reality of carers of persons with HIV/AIDS. Often they face the death of their loved ones in the context of social rejection. Literature and stories in the media on gay men who are carers especially abound with this poignant reality. Some authors (Fontaine & Reidy, as cited in Reidy, 1997; Rando, 1988; Regnier, as cited in Reidy, 1997) found that this complex situation leads to strain in the relationship between carer and the cared-for. They go on to suggest that at times this could lead to premature disengagement and abandonment by the family. This situation may lead to the cared-for being physically and emotionally abandoned, and the carer guilty with unresolved grief.

The literature also alludes to the positive effect of caring. Often the burden of caregiving is balanced by its rewards. Reidy and Taggart (as cited in Reidy, 1997) found that carers felt that taking care of their loved one actually gave a meaning to their lives, a reassurance and sense of well-being and worth. Sometimes the crisis of illness may also serve to reunite the family (Miller & Goldman, 1993).

It can be seen that caring for a family member with HIV/AIDS presents multiple challenges to the carer and to the family. The carer's response to these challenges will help determine how well he or she fares as the caring process continues, and will also influence the well-being of the family as a whole. In the next section, the efforts of the carer and the family to cope with the stresses outlined above will be examined.

Family Caring and Coping

The diagnosis of HIV/AIDS in a family brings with it psychological disturbances and upheavals. The extent and range of emotions experienced is unique in all individuals, and is dependent on the person's life experience and the psychological condition before the advent of HIV/AIDS. One important aspect of the person's response to stress is the effort to cope.

Coping may be seen as a set of steps taken by the individual to adapt to a stressful situation. Psychologists distinguish two broad types of coping strategies: problem-focused coping and emotion-focused coping. The goal of both strategies is to control one's stress level. In problem-focused coping, people try to short-circuit negative emotions by taking some action to modify, avoid, or minimize the threatening situation. They change their behaviour to deal with the stressful situation. Problem-focused strategies include gathering information, planning, and taking direct action. In general, problem-focused coping is seen as the most effective coping strategy when people have realistic opportunities to change aspects of their situation and reduce stress.

In emotion-focused coping, people try to directly moderate or eliminate unpleasant emotions. Examples of emotion-focused coping include rethinking the situation in a positive way, relaxation, denial, and wishful thinking. Other emotion-focused strategies include efforts to escape or avoid problems, emotional outbursts, and self-accusation. Emotion-focused coping is most useful as a short-term strategy. It can help reduce one's arousal level before engaging in problem-solving and taking action, and it can help people deal with stressful situations in which there are few problem-focused coping options.

The literature identifies strategies utilised by carers to cope with the stress, burden and pain they experience. Some authors (Greif & Porembski, 1988; Pearlin et al., 1988; Reidy & Taggart, 1995) enumerate these: an attempt at changing the situation; an attempt to change or reduce the negative connotation and feelings of fear and threat; maintaining and/or controlling anxiety levels; finding solutions to problems; encouraging self affirmation and participation in social or political action in the field of HIV/AIDS, thereby ending and not supporting the conspiracy of silence; and reaffirmation of religious and spiritual beliefs. It can be seen that these strategies include a mix of problem-focused and emotion-focused strategies. Research on coping in general suggests that caregivers who use more problem-focused strategies to cope with stressful situations are less likely to experience burnout than those who use emotion-focused strategies (Billings et al., 2000; Kalichman et al., 2000; Pakenham & Dadds, 1995). However, emotion-focused strategies may be beneficial in situations where no problem-focused option is available. This is often the case when dealing with HIV/AIDS in a family member.

A few studies have examined the impact of different coping strategies on the functioning of those who act as carers for family members who are ill. Borden

(1991) studied family carers for aged individuals with Alzheimer's disease and found that carers who used problem-focused coping strategies tended to function better. Morano (2003) also studied family carers of Alzheimer's patients and looked at the question of whether different coping styles moderate the effect of stress. She found that emotion-focused coping helped to moderate the effects of stress, decreasing the depression and increasing the life satisfaction of the carers. This study failed to find any moderating effects for problem-focused coping.

In contrast, Folkman (1997) found that problem-focused coping was helpful for carers of HIV/AIDS patients, by helping to increase their sense of positive meaning in the role they were performing. She also found that, although caregiving produced stress and negative consequences initially, families tended to take a longer view of caregiving that eventually led to the experience of more positive outcomes. She suggests that this view was integral to the way in which they coped.

Billings et al. (2000) examined coping strategies for HIV/AIDS carers and found that socially oriented coping strategies, such as talking with others, increased the positive affect of the carers, which in turn helped them to avoid physical symptoms associated with caregiving. This study also found that individuals who engaged in self-injurious behaviours to avoid dealing with the problem, such as drinking or drug use, experienced more negative physical symptoms associated with caregiving.

Taylor's (1983) Cognitive Adaptation Model, which was developed from a study with women living with breast cancer, is a useful model in understanding how carers cope with HIV/AIDS. Coping mechanisms, such as having high self-esteem and maintaining a sense of power over one's fate or karma offer a means of coping and ways to live with HIV/AIDS. Carers living with HIV/AIDS may use a full range of coping strategies. These include emotion-focused coping strategies that improve how a person feels without addressing the problem and problem-focused coping strategies that target the source of stress.

The success of the family's coping efforts may depend on the resources available to the family to use in coping. Direct efforts to reduce stress by improving the health of the HIV/AIDS–affected person require resources such as access to medicines and medical care, money for food, medicines, and other needs, and a range of other material resources. More indirect coping efforts may also require resources, such as an appropriate social support network or counselling services.

One of the key resources for coping may be the availability of some form of social support. Social support refers to the interactions and interrelationships in family life, recreation, health and social services (Kristjanson & Chamers, 1991; Lieberman, 1988). Thoits (1986) has noted the importance of social support as an aid in coping with stress in general, and Hart et al. (as cited in Reidy, 1997) and McGough (1990) argue that the impact of caring for a person with HIV/AIDS may be alleviated by social support. A study by Kelly and Lawrence (1988), suggests that families whose support needs are not met during the caretaking of a family member with AIDS experience more depression, fatigue, guilt, anger, helplessness and illness than families who felt their needs were met.

Often with the social disruption caused by HIV/AIDS however, the carer and the person living with HIV/AIDS are denied the support available to persons living with other chronic illnesses. This could either be on account of non-disclosure or due to stigmatisation around HIV/AIDS, thus increasing the burden and stress of care giving (Fortin et al., 1989, as cited in Reidy, 1997; Reidy, 1997).

Providing care to a spouse or partner who is dying and then losing that person are among the most stressful of human experiences, yet it may have positive aspects as well. A longitudinal study of the caregiving partners of men with AIDS showed that in addition to intense negative psychological states, these men also experienced positive psychological states throughout caregiving and bereavement (Folkman, 1997). The co-occurrence of positive and negative psychological states in the midst of enduring and profoundly stressful circumstances has important implications for the understanding of the coping process. Coping theory had traditionally focused on the management of distress. This article describes coping processes that are associated with positive psychological states in the context of intense distress and discusses the theoretical implications of positive psychological states in the coping process.

Results show that the lives of men providing care to a partner dying of AIDS are chronically stressful, with unrelenting demands for care and emotional support. They were also faced with an ongoing threat to their own health and well-being. Nevertheless, in the face of extreme and chronic stress, these men were able to report events that were meaningful, positive, and accessible on a daily basis.

The literature on the coping efforts of family carers in HIV/AIDS is somewhat limited, and the studies suggest a complex picture of the strategies that carers may use to deal with the multifaceted stresses of caring for a loved one with HIV/AIDS. It appears that both emotion focused and problem focused coping may be beneficial, depending on the circumstances. The availability of resources for coping—particularly social resources—is also an important consideration. The next section examines the influence of caregiving stress and coping on the mental health of family carers.

Family Caring and Mental Health

Many aspects of caring for a family member with HIV/AIDS suggest that providing care would have a strong impact on the mental health of the family carer. As explained earlier, many aspects of caring in this situation are stressful, including the many threats to the family's material, emotional, and social welfare. The spectre of loss often looms over family carers, who must anticipate the death of the HIV/AIDS-affected member and must witness an often painful deterioration. Worries about financial issues, physical and emotional exhaustion, and uncertainty can also add to the emotional burden.

Marium and Boyd (as cited in Reidy, 1997), in their review of literature on the impact of mental illness on the family, and Brown (1993) in her study of persons living with HIV/AIDS, suggest that illness has an effect on every sphere of the carers' lives. Further they suggest that the impact is cumulative with the progress of time. Brown (1993) found the effect of caring for persons living with HIV/AIDS ranged from having less energy for work to loss of energy for quality of life activities. Further, Brown found that many families reported being "managed by HIV" rather than "managing" it.

HIV/AIDS has intense and wide-ranging psychological effects on persons caring for PLWHA (King, 1993; Moss, 1992; Squire, 1993). Family caring for HIV/AIDS-infected persons through various stage of the illness are subject to severe emotional and mental trauma as they care for their dying loved ones. Those caring for the dying PLWHA are sometimes themselves HIV positive and are traumatized by witnessing the effect of the disease on their loved ones and are terrified of going through the same slow and torturous death. In addition, they face stigma and discrimination from other family members and society. In cultures marked by a high degree of stigmatisation of HIV/AIDS, HIV-positive wives may care for their husbands until their deaths, after which they may be turned out of their homes; hence fear of losing a home to stay in constantly stalks them. Frequently elderly parents have to care for dying sons and daughters and grandchildren, which causes them a huge financial burden as well as psychological trauma. Lack of support from society and friends often lead to emotional burnout.

Families of HIV/AIDS patients thus face multiple stress factors and tensions. In addition to the eventual death of the family member with HIV/AIDS, family members often must come to terms with their feelings about the patient's lifestyle and with their own fears about contracting the illness. Owing to all these pressures, there is a higher chance for the family members to develop emotional and psychological problems.

Several studies have examined the psychological consequences of caregiving. These studies have been fairly consistent in demonstrating an association between caregiving and various symptoms of both physical and emotional distress. Schulz et al., (1990) and Wright et al., (1993) both demonstrated negative emotional consequences associated with caring for a frail elderly person. Some authors (e.g., LeBlanc, Aneshensel, & Wright, 1995; Powell-Cope & Brown, 1992) have speculated that these consequences may be somewhat more severe in the case of carers for those affected by HIV/AIDS, because of the negative social climate and atmosphere of secrecy associated with HIV/AIDS.

Miller (1987) points out that many studies of carers of the chronically ill have shown that carers actually have higher rates of depression and anxiety than the persons they are caring for. He points that where the diagnosis is kept hidden from others, the strain that develops from bottling up the tremendous stress and worry can lead to serious mental and physical consequences. Additionally, he suggests that some carers also suffer from the disease, although they may not actually have it. Family carers of persons living with HIV/AIDS have the additional and very real burden of worrying about the possibility of their own infection.

Caregivers under stress exhibit a wide range of signs and symptoms, which may be very similar to those experienced by the person with HIV/AIDS. The extent to which caregivers experience these symptoms depends on their personalities, belief systems, health and energy levels, and coping skills (Turnbull et al., 1999). Additional factors affecting caregivers' response to stress include the severity of the care recipient's illness, the duration of caregiving, and the accessibility of social support and financial resources (Oberst et al., 1989; Pearlin et al, 1997; Wight et al., 1998).

Help Age International/International HIV/AIDS Alliance (2003), in a study conducted with older family carers found that together with stigma and exclusion, carers experienced psychological problems of grief, loss, anger, fear, stress, worry and sleeplessness. Pearlin et al (1988) and Lennon et al., (1990) both found high levels of emotional distress among HIV/AIDS caregivers. LeBlanc et al. (1995) looked at depression and use of psychotherapy among HIV/AIDS carers, and found elevated levels of depression among caregivers, which in turn was associated with higher use of psychotherapy.

One common reaction that might be expected in the circumstance of family caring for HIV/AIDS is anxiety. The many uncertainties surrounding the progression of the illness can engender significant anxiety for the family carer. This anxiety may be exacerbated by financial worries, fears of social ostracism, and changes in family relationships and behaviour patterns.

Loss is another key issue that might be expected to arise for family carers. The family member who has AIDS, whom they love, is quite likely to die, and adapting to the loss of a loved one is one of life's most stressful events (Osterweis et al, 1984; Videka-Sherman, 1982). Although normal bereavement is not usually considered to be a mental disorder, the complicated aspects of mourning for a family member with HIV/AIDS can often exacerbate the normal grief reaction and lead to significant mental health difficulties. Feelings of ambivalence towards the loved one, which are not uncommon given the circumstances of HIV infection for many individuals, may exacerbate the experience of bereavement. Memories of and grief about previous losses may also be evoked, giving rise to a climate of depression and mourning, perhaps inexplicable to outsiders. Mourning involves emotional, physical and spiritual reactions which force carers to feel abandoned, confused, depressed and sometimes suicidal. It is a time when there are emotions of relief that the dying process is over, mingled with evocative memories, regret, loneliness, and great sadness (Parkes, 1972).

Even while the person with HIV/AIDS is still alive carers may experience anticipatory grief as they foresee the death of the loved one. In these circumstances, significant others may need an opportunity to discuss their anger and conflicts concerning the loss of the patient. These factors can complicate and intensify the mourning process following the person's death (Koocher, 1986). Difficult though it may be, bereavement is a universal experience and the families of the person with HIV/AIDS have to cope with this reality. Experiencing the possibility and then the reality of losing a member to this disease is a unique and particularly difficult circumstance (Kelly & Lawrence, 1989).

Although family carers seem to be at risk for developing mental health issues as a result of their caring experience, the existing literature in this area is still fairly limited. The studies that exist are consistent in suggesting higher levels of psychological distress among carers, including anxiety, depression, and exhaustion; nonetheless, additional research is needed to develop a more complete picture of the needs of carers as they deal with the complex and often painful circumstances of caring for a family member with HIV/AIDS.

Conclusion

This chapter provides a background for the research by reviewing the literature in the fields of HIV/AIDS, the family, coping and mental health. It points to the need for further empirical knowledge in these areas, and the present study attempts to fill some of these gaps.

The section on HIV/AIDS provided a brief background on the epidemic as it has been manifested in Kerala and Scotland, the two areas of relevance for this study. The next section examined the phenomenon of family caring for HIV/AIDS, looking at the changing definition of family; the roles and tasks of caring; the stages of the caring process; the physical, emotional, social, economic, and family relationship effects of caring; and family caring as a source of stress. This section was followed by a section that examined the phenomenon of coping as it applies to family caring for HIV/AIDS. In the final section, the effects of caring on mental health were examined.

Although there is a growing body of research on many aspects of HIV/AIDS, relatively little attention has been paid to the experiences of family carers, particularly those in developing countries. The well-being of these carers, who are often the mainstay of treatment and care for PLWHA, is an important element in the overall impact of the HIV epidemic, and further understanding of this phenomenon is necessary. In particular, it is important to understand how family carers cope with the many burdens they experience and to develop insight into the short- and long-term consequences of the caring experience for their mental health.

The next chapter discusses the socio-economic, cultural and developmental issues that reflect the ground realities of the two contexts of the study: Kerala and Scotland. The chapter also explores aspects of HIV/AIDS care in both contexts.

CHAPTER 3: THE SOCIAL AND DEVELOPMENTAL CONTEXT OF THE STUDY

Introduction

The previous chapter reviewed the body of literature in the fields of HIV/AIDS, family caregiving, coping and mental health. This chapter discusses the relationship between HIV/AIDS and development and explores the ways that HIV/AIDS undoes the progress in development made by a community. It proceeds to look at the two settings in which the data were collected: Kerala and Scotland, through the lens of development, and provides specific information about six key aspects that varied significantly between the two contexts and impinged on the daily lives of carers: social realities, economic realities, health care systems, formal and informal support systems for carers, services for HIV/AIDS, and statutory provisions for family carers.

By developing an understanding of the carers' social and developmental context, this chapter throws light on their background and shows how that background could affect their capacity to provide care and support to their family member living with HIV/AIDS. Moreover, by elucidating the socio-cultural background of the carers, the chapter highlights the ethos of caring for a family member living with a chronic, stigmatising illness.

HIV/AIDS and Socio-Economic Development

One of the key concepts that appears in much of the literature concerning the HIV/AIDS epidemic is that of development. HIV/AIDS and development are inextricably interconnected, and an understanding of this relationship is crucial in developing an insight into the two socio-economic contexts of this study and its participants.

HIV/AIDS is increasingly considered as an issue of economic and social development (Altman, 1993; Madavo, 1998). Nishimizu (2002) characterizes

HIV/AIDS as “a singularly most critical socio-economic development issue” (p.1), because the epidemic is turning back the “clock on development” (Wolfensohn, 2000, p.1) especially in the developing world, where it is cutting down and impoverishing life and vital human investments. Moreover, at the household level, it hits families where it hurts most— undermining family earning power by cutting down adult members during their most productive years. Additionally, HIV/AIDS and poverty together create a vicious circle, where HIV thrives on poverty while deepening it (Global Forum for Health Research, 2002). Therefore, the poorest countries are unequally hit by the epidemic. For example, in India the HIV/AIDS epidemic threatens the country's achievements in health and development. Global experience suggests that the epidemic reduces life expectancy, increases the demand for medical care, worsens other illnesses such as tuberculosis, and exacerbates poverty and inequality. The United Nations Development Programme’s (UNDP) annual Human Development Report for 2003 states that, due primarily to HIV/AIDS; life expectancy has fallen in 34 countries (United Nations Development Programme, 2003).

AIDS can be understood as a disease of poverty, because the epidemic has struck particularly hard in the poorer countries. Although HIV infection rates are declining in the developed world, they are stable or rising in most developing countries. HIV/AIDS deepens and spreads poverty (Lyons, 1998), because poor households are more adversely affected by an AIDS death of a prime-age adult than other households. Poor households have fewer assets to draw on to cope with medical expenses and the loss of income and services that a prime-age adult typically provides. Thus, HIV/AIDS is likely to increase poverty through the rise in the number of children who lose one or both parents and orphans consequently have significantly lower school enrolment rates and are more likely to be malnourished than non-orphans. Lack of schooling and inadequate nutrition will make it more difficult for children orphaned by HIV/AIDS to escape poverty as they mature.

Further, HIV/AIDS forces countries to make tragic choices between health and the dozens of other vital investments for development, and finally, labour migration, urbanization, and cultural changes, all factors of development itself, contribute to the spread of the HIV/AIDS epidemic (Madavo, 1998; Nishimizu, 2002).

This inextricable relationship between HIV/AIDS and development is reflected in the capacity that HIV/AIDS has to undermine significant improvements in health indicators and to aggravate prevailing economic problems (Biggar, 1988; Hankins, 1997). It can also intensify poverty and retard access to education, health care, and viable livelihoods (UNAIDS, 2002). HIV/AIDS claims the lives of the most productive members of society, leaving behind their children and the elderly struggling to care for those who survive. The epidemic can thus derail the advances in development made by a community. At the same time, such consequences of underdevelopment as poverty, malnourishment, inadequate health care, low respect for human rights, lack of education, poor housing, exploitation and discrimination of women, and insensitive political systems all heighten the impact of HIV/AIDS on society (Moerkerk, 1992). Further, the social and public health conditions created by HIV/AIDS tend to increase the risk of new infection among the poor and the disenfranchised, further spreading the epidemic.

For the reasons outlined above, the HIV/AIDS epidemic has provoked a developmental crisis in major regions of the world (Barnett & Whiteside, 1999) and is therefore regarded as a disease of development and under-development (Schoepf, 1993). Countries that fail to bring the epidemic under control risk being engulfed in a vicious circle of decline in socio-economic conditions (UNAIDS, 2002, 2004a). Barnett and Whiteside (2002) point out that the HIV/AIDS epidemic can be viewed as a "long wave event," whose impact takes place over many decades, creating impoverishment that could last as long as a century. They argue that "by the time the wave of HIV infection makes itself felt in the form of AIDS illnesses in individuals, the torrent of the epidemic is about to overwhelm medical services, households and communities" (p. 16). They also note the likely influence of the phenomenon of globalisation on the HIV/AIDS crisis. Although it is still unclear how globalisation will influence the epidemic and the response to it, they point out that HIV/AIDS presents new challenges that may require a rethinking of the very concepts of public health and well-being. He calls into question the effort to think of health care in strictly economic terms, and notes that ethical issues related to the very definition of health and well-being are raised by the phenomenon of worldwide HIV/AIDS.

Although AIDS was first described as an illness of homosexual men living in urban, developed countries, today's unfortunate reality is that the large majority (95%) of persons with HIV/AIDS live in the developing world (Population Council and International Family Health, 2001). Because HIV/AIDS spreads readily in areas of urban poverty, poor health care, social disintegration, and pre-existing social and health problems, the problem of HIV/AIDS is more complex in developing countries (Miller & Rockwell, 1988). AIDS will "alter the history of many of the world's poorest societies" (Barnett & Whiteside, 2002, p. 21).

As stated earlier, the HIV/AIDS epidemic undermines earlier progress and reinforces some of the worst facets of underdevelopment (Moerkerk, 1992). One of the most important Third World achievements, the reduction of disease, is not only retarded, but there is the threat of completely reversing the process. The presence in the population of individuals whose immunity is compromised allows for the proliferation of diseases, such as tuberculosis, that had previously come under relative control in many parts of the world. Life expectancy rates also begin to fall as AIDS affects young and middle-aged adults in their most productive years, leaving behind a population who is more vulnerable (Bharat et al., 2001). Moreover, hunger, malnutrition, poverty, lack of hygiene and sanitation, natural calamities, and internal strife, all aspects of underdevelopment, reduce the visibility of the AIDS pandemic (Paicheler, 1992) and thus reduce the likelihood that the problem will be attacked directly. Thus, in the words of Wolfensohn (2002), "HIV/AIDS is reversing decades of development gains, increasing poverty and undermining the very foundations of progress" (p. iv).

Lastly, there is an inseparable link between poverty, health, education, development and HIV/AIDS. Poverty and health are inextricably linked and that they share a complex relationship. Poverty is one of the key determinants of ill-health. The poor represent a quarter of the world's population of over five billion people; they share a disproportionately large burden of ill health (Global Forum for Health Research, 1999, 2000). The United Nation Development Programme's World Summit on Sustainable Development (2002) points out that lack of education leads to poverty. Lack of education also contributes both directly and indirectly to the spread of HIV infection. Ignorance about the causes and spread of HIV lead to high risk behaviours, which directly increase the likelihood that an individual will contract HIV. Lack of education also contributes indirectly to the spread of HIV/AIDS, by fostering conditions of powerlessness and desperation, increasing vulnerability to high-risk behaviours such as drug use and participation in the sex work. While HIV causes AIDS, the epidemic itself is driven by the interaction of many aspects that include poverty, stigma, discrimination and marginalisation. Poverty is in actual fact both a cause and a consequence of the epidemic (Canadian International Development Agency, 2002). Education, which is central to development, leads to empowerment, which is a key to eradicating poverty and combating HIV/AIDS, both of which are listed among The United Nation's Millennium Development Goals (World Bank, 2004).

Kerala and Scotland through the Lens of Development

Because of the connections between issues of development and the HIV/AIDS epidemic, it is important to understand how these issues come into play for the populations included in the present study. Thus this section views Kerala and Scotland through the lens of development, thereby providing insight into the socio-economic context of the carers in each community.

Kerala is a constituent state of India, which is a developing country. Kerala lies at the southwest end of the Indian peninsula. Formed in 1956, it is one of the smallest states in India, with 14 districts. The capital is Thiruvananthapuram, formerly called Trivandrum. The state, with a total population of approximately 32 million, recorded the lowest population growth rate of 1.34 percent, against the national average of 2.14 percent during the decade 1981-91 (UNFPA, 2001). Over 51 percent of the population are females, and roughly 49 percent are males (Government of Kerala, 2002). According to United Nations (1991) the state has the distinction of having achieved 100 percent literacy (McKibben, 2005).

Scotland is one of the four constituent countries that form the United Kingdom. It forms the northern part of the mainland. The twin cities of Edinburgh and Glasgow have a population of 430,082 and 629,501 respectively (Scotland's Census Results Online, 2005). Edinburgh is the capital of Scotland, and has been called the "AIDS capital" of Europe (Des Jarlais & Case, as cited in Levine, 1994; Welsh 1994), because of the high prevalence of HIV/AIDS during the early days of the epidemic in the United Kingdom.

Social Realities

As suggested earlier, the social realities that existed in Kerala and Scotland vary significantly because the two countries belong to different contexts of social development. The paragraphs below will provide some details of the differences between the two settings.

Human Development Indicators

The Human Development Indicators (HDI) are a system developed by UNDP for measuring and monitoring the human dimension of development. The main underlying principle of the indicators holds that while growth in national production (GDP) is crucial to meet all essential human objectives, what is even more essential is how this growth translates, or fails to translate, into human development in varied communities. These Indicators differ from conventional approaches to economic growth and development. They view human development in terms of the process of widening people's choices and the level of their achieved well-being, and focus on three crucial elements of human existence: life expectancy (a proxy indicator for longevity), educational attainment (measured by literacy and school enrolment rates) and standard of living (measured by real GDP per capita) (Barnett & Whiteside, 2002). In constructing the human development index, UNDP uses a deprivation measure of these three essential elements; that is, it measures the continuing shortfall from a desired value or target, rather than what has been achieved. For each of these indicators, countries are ranked according to low human development, medium human development, and high human development (World Resources Institute, 2003). A higher score on the HDI indicates a lower level of development. The differences between the two contexts used in this study are portrayed in the distance between the HDI for India and Scotland for the year 2003, which ranks India at 127 (three ranks lower than for the year 2002) and the United Kingdom at 13 (United Nations Development Programme, 2003). Loewenson and Whiteside (2001) argue that nations affected by the HIV/AIDS epidemic are slipping down the Human Development Index; a trend which, they point out, will continue and worsen as current cases of HIV-positive persons develop AIDS.

However, although the HDI are helpful in reflecting the differences between the socio-economic contexts of the two settings, it must be noted that the HIV/AIDS epidemic, though already in its third decade, has not been taken on board by the international development community. Although the UN includes HIV/AIDS in its Human Development Reports, there is little appreciation of what HIV/AIDS means for developmental targets (Barnett & Whiteside, 2002).

Kerala's Unique Model of Development

There is an inextricable link between poverty, health, education, and development. However, it could be argued that Kerala's unique model of development presents a contradiction. Kerala demonstrates that people in the Third World can make their lives better in the absence of industrialization or large-scale economic growth, through the elements of active grassroots organizations, redistribution of wealth, and democratic participation. The main elements of the Kerala model include a land reform initiative that has abolished tenancy and landlord exploitation, effective public food distribution that provides subsidized rice to low-income households, protective laws for agricultural workers, pensions for retired agricultural labourers, and a high rate of government employment for members of formerly low-caste communities (Franke & Chasin, 1995).

Dreze and Sen (1999) argue that Kerala provides a unique model of development because it has been able to achieve exceptional social development in areas such as health, education, and even the demographic transition, despite low economic development and low per capita income. Moreover, despite low per capita incomes, Kerala has achieved nearly total literacy, long life expectancy, low infant mortality and birth rates, and high access to medical care. Kerala's development indicators compare favourably with the rest of India, with low-income countries in general, and even with rich nations such as the United States.

Kerala demonstrates that basic health care, literacy, and social integration can be achieved at relatively low cost, given a high level of political investment and leadership. Social development indicators reflect the relatively good performance of Kerala in this area. These include a maternal mortality rate below 200 per thousand and an infant mortality rate of 16 per thousand (compared with a national average of 73). The ratio of males to females of 103 to 100 is close to the biological norm, as compared to the 93 to 100 norm for the rest of the country (Registrar General & Census Commissioner, India, 2001). Kerala's peasant associations and unions have also fought for public health measures and access to health care. Kerala continues to be the only Indian state with no major statistical evidence of excess female mortality—a sign that female children in Kerala have equal life chances to those of males (Franke & Chasin, 1995).

Kerala has the highest immunization rate in India and more than three times the number of hospital beds per capita compared to the rest of India. The average person born in Kerala today lives to age 72, almost 12 years longer than someone born elsewhere in the country. The infant mortality rate is less than one-fourth that of the country as a whole. These statistics move towards American and European levels, and they are better, in fact, than those for black Americans. Only 30 years ago, Kerala had the fastest-growing population in India, but today the state's birth rate is 1.7 children per woman. A generation from now, Kerala's population will level off and begin to drop. Figures like these are all the more conspicuous, because Kerala has attained them with a per capita income that, on paper, is only about 1/70 that of the United States (Hochschild, 1999).

Literacy and Education

Kerala stands in the forefront of Indian states in relation to its literacy and education. Kerala is the only state among India's 25 states that is said to have almost 100 percent literacy (Newton, 2001), with a male literacy rate of over 94 percent, and over 87 percent for females (Government of Kerala, 2002). This literacy rate is more than double that of the rest of India. It is significant that Kerala is almost on a par with the most advanced countries of the world in relation to literacy (Government of Kerala, 2005).

Similarly, in Scotland, the Scottish Executive's national priority for education is to raise the standards of literacy and numeracy. Education and literacy are given a very high priority. Although literacy rates were not available for Scotland alone, the reported literacy rate for the United Kingdom as a whole is reported as 99 percent (Central Intelligence Agency, 2003).

HIV/AIDS and Social Stigma

Kerala's socio-economic and cultural realities present paradoxes. Even though Kerala is a socially advanced state, there are some regions where the broad spectrum of developmental indicators is low (UNFPA, 2001). Thus, south Kerala presents high developmental indicators as compared to north Kerala, and likewise the differences between the urban and rural areas are also quite visible. Moreover, although Kerala is regularly commended for its spectacular health and literacy achievements, it has been found that the people of Kerala can be guilty of stigmatising HIV/AIDS (Newton, 2001). It is perhaps possible to imagine that a population with high literacy, social and economic growth and political awareness would have a greater understanding of and tolerance towards people with HIV/AIDS. However the stories of people who have experienced HIV-related stigma and discrimination do not correlate with the notion of social and economic development reducing HIV-related stigma. The problem of stigma that continues to trouble many HIV/AIDS patients in India (Bharat et. al,

2001) is very much a problem in Kerala, often denying them access to health care and forcing HIV/AIDS-positive persons and their carers to suffer in the shadows, and sometimes forcing them to flee for their safety.

In Scotland, HIV/AIDS is commonly associated with sexual promiscuity and drug use, and therefore it carries a stigma. Over the past three decades there has been a shift in the general awareness patterns and an understanding of the nature of HIV and its transmission; however, accounts of carers in Scotland (Pollock, 1999) reflect feelings of alienation and isolation, the strong stigma attached to HIV/AIDS, and the ostracism of persons with HIV/AIDS and their families.

Economic Realities

There is no economy in the world that remains unaffected by the HIV/AIDS epidemic. HIV/AIDS is a huge threat to economic stability and growth in both developed and developing country contexts. However, the devastating effects on economies and markets are more visible and felt more fully in the developing world context. The economic contrast between both the communities is clearly revealed in the large gap between the Gross Domestic Product (GDP). According to 2002 estimates, the GDP per capita in India was $2,600 as compared with $ 25,500 in the UK (Central Intelligence Agency, 2003).

Unemployment

The state of Kerala, which spends proportionally more on education than any other in India, has the country's highest unemployment rate: three to four times the national average. The high unemployment rate, coupled with the high literacy rate, has compelled young people from all walks of life and all vocations and professions to search for jobs outside of Kerala. Many have travelled to the metropolitan commercial capital of India—Bombay. Moreover, for several years starting in the early 1970's, the Arabian Gulf countries provided a refuge of hope and survival for thousands of households across Kerala. With the increasing visa restrictions, the fall in wages, and the "Arabisation" of the Gulf, many "Gulf Returnees", as they are called, have been forced to make a large-scale exodus from the Arabian Gulf back to

Kerala, inevitably having a negative impact on their financial stability. This aspect of employment is particularly significant to the epidemiological understanding of HIV/AIDS in Kerala, and it is critical to understanding how the HIV/AIDS epidemic impinged on the lives of HIV/AIDS-positive persons and on their family carers. Bombay, which has been dubbed the "AIDS capital" of India (Bharat et al., 2001) and the "AIDS capital" of the world (Specter, 2001), was a place of employment for large numbers of men, but it was also a port of embarkation and disembarkation to and from the Gulf. Men who migrate from their homes and live away from their families are more likely to engage with sex workers. According to a Press Trust of India report (2001), incidence of HIV/AIDS was the highest among people who had gone out of the state of Kerala in search of employment.

The employment scenario in Scotland differs greatly from the one described in Kerala. This is primarily because Scotland is a welfare state. The concept of a welfare state emerged following the recommendations of the Beveridge Report, (1942), and refers to the state's provision of public measures and support to achieve basic living standards and help those in need across society. It also aims to relieve poverty, reduce inequality, and achieve greater social integration and solidarity. The Beveridge Report led to the establishment of a national health service, national insurance and assistance, and family allowances. It also stressed the importance of full employment (London School of Economics & Political Science, 2000).

Thus the government of Scotland makes every effort to increase employment opportunities and to reduce unemployment rates. This is facilitated through the creation of Job Centres and other statutory provisions, such as Income Support or Income based Job Seekers Allowance. The latest figures from the Scottish Executive (2003) reveal that unemployment levels have fallen since 1997 from 8.5 percent of the working-age economically active population to 5.5 percent.

Poverty

The experience of poverty has a profound effect on the lives of carers. Dr Gro Harlem Brundtland, Director-General of the World Health Organization, describes

HIV/AIDS as a disease of poverty (African Online Services, 2003), and this sentiment has also been expressed by several others (Aggleton, 1996; Ankrah 1991; Collins & Rau, 2000; Connors & McGrath, 1997; Farmer et al., 1996; Schoepf 1993; UNAIDS, 2001b). As noted earlier, while HIV/AIDS affects people from all classes, it hits particularly hard among the poor and is more likely to proliferate among the poor. As Foreman et al., (1992) argue,

> *With certain exceptions, the overriding reason for the rapid spread of HIV has been the high correlation that exists between poverty and vulnerability to the virus, a correlation that has led to high rates of infection in the most economically deprived populations of cities as far apart as Bombay, Edinburgh, New York and Rio de Janeiro (p.10).*

The relationship between poverty and HIV/AIDS is bi-directional. Poverty is a factor in HIV transmission and in exacerbating the impact of HIV/AIDS. The experience of HIV/AIDS by individuals, households, and even communities that are poor can readily lead to an intensification of poverty and even push some non-poor individuals into poverty. Moreover, poverty can also accelerate the onset of AIDS and tends to increase the impact of the epidemic (Collins & Rau, 2000). Thus, as the HIV epidemic makes sustained human development more unattainable and actually adds to poverty, it also destroys the human resource capacities essential for an effective response (Cohen, 2005) and perpetuates the poverty of individuals, families, and societies (Brundtland, 2002).

There is no simple association between any one factor of poverty and the risk of HIV infection. There is, however, a link between people's lack of access to resources and economic strategies adopted to survive (Lindenbaum, 1992). While not a direct cause of the disease, poverty can create an environment that fosters the spread of AIDS.

Poverty is experienced differently in Kerala and Scotland, and can be viewed from the two perspectives: absolute and relative. However, the idea of absolute poverty is a contested concept (Gordon et al., 2000), and definitions of absolute poverty tend to vary considerably and are based on the assertions of experts about the minimum needs of people (Gordon & Spicker, 1999).

Relevant to this discussion is the debate on the concept of absolute poverty between Sen and Townsend (Gordon et al., 2000). Sen (as cited in Gordon et al., 2000) argued that if hunger and starvation exist, there clearly is poverty, no matter what the relative picture appears to be. He suggested that there is an irreducible core in the idea of poverty that is the need to meet nutritional requirements, to be sheltered, to be educated, and to be clothed. Townsend (as cited in Gordon et al., 2000) responded that this absolutist core is itself relative to society, and those notions of nutritional requirements, shelter, etc. are dependent on different cultures. For example, the idea of shelter is relative not just to climate but includes notions of privacy, space to work, play, etc., as well as highly cultured notions of warmth, humidity etc. However, Sen (as cited in Gordon et al., 2000) argues that the characteristic features of absoluteness do not depend on either constancy over time or upon invariance between societies. Moreover, Townsend and Gordon (1991) argue that if absolute poverty is defined in terms that are neither constant over time nor invariant between societies, then from an operational point of view, the concepts of absolute and relative poverty become practically indistinguishable and thus can be measured and investigated scientifically using standard social survey methods.

In this study, the concept of absolute poverty is relevant for those sections of Indian society who lack the basics of food, clothing, and shelter necessary to subsist (Beresford et al, 1999). In India, carers of family members living with HIV/AIDS often belong to that deprived section of society.

Although Kerala is considered to be a part of a developing country and Scotland is a part of the developed world, it is important to recognise that there are areas in Scotland characterised by poverty and deprivation. A study carried out by the Townsend Centre for International Poverty Research (1999) identified Anniesland, Springburn, Maryhill, Shettleston, Pollok, and Baillieston in Glasgow as being among the worst poverty spots in Scotland. However, in general the experience of poverty in the context of carers in Scotland may be described as relative rather than absolute, because although the carers have sufficient resources to meet their basic needs, they lack the resources, amenities, and living conditions that are customary to the society they belong to and are considered as essentials (Mack & Lansley, 1985; Townsend, 1979).

Statistics reveal that the number of people in Scotland living in relative poverty has more than doubled over the past 20 years. The Scottish Executive's Social Justice Annual Report (2000) states that 21 percent of households with adults of working age have no one in work. The proportion of children in Scotland living in households with relatively low incomes increased two and a half times (to 1 in 3). The proportion of Scottish children being brought up in workless households doubled (from 13.7 % in 1979 to 26.4 % in 1997). People from the poorest areas in Scotland are now nearly three times as likely to die early than people from the richest areas. Life expectancy at birth in Scotland is two years less than in England and Wales.

According to the Scottish Household Survey (Scottish Executive, 2000) the majority of households in the categories "disadvantaged council estates", "families in council flats" and "renting singles" have no working adults. Twenty percent of unemployed adults have been unemployed for more than 5 years, and 52 percent of households have a net annual household income of £10,000 or less. Two thirds of single parent households have a net annual household income of £10,000 or less. Households in the "families in council flats" category are most likely to be in the lowest income banding. Levels of participation in education and training differ by household type. The lowest participation levels are found in "better off council", "disadvantaged council estates" and "families in council flats". Forty percent of "families in council flats" have no educational qualifications, compared with 8 percent of adults in high income areas. The likelihood of a household containing at least one person with a limiting long term illness or disability rises as household income decreases.

Finally, Galloway (2004) suggests that poverty is still seen in its starkest form in Glasgow. It contains 78 percent of Scotland's most deprived areas. Within Glasgow, 277,000 people live in an area of deprivation—42 percent of the city's population. Across the UK as a whole, Glasgow has the second highest percentage of households with no earner in the family.

Health Care Systems

Caring for and supporting persons living with HIV/AIDS is best addressed through a care continuum that includes prevention as well as medical care, traditional care, nursing care, counselling, and social support services (Macinnis, 1997). This section briefly discusses the differing health care systems that are available to persons with HIV/AIDS in the two contexts and briefly points to the impact these systems have on the carers.

One important indicator of the level of care available for HIV/AIDS patients is the availability of specific treatment for HIV, such as the HAART, composed of multiple anti-HIV drugs prescribed to HIV-positive people even before they develop symptoms of AIDS (and without considering that many will never develop these symptoms). The therapy usually includes a combination of drugs: one nucleoside analog (DNA chain terminator), one protease inhibitor, and either a second nucleoside analog or a non-nucleoside reverse transcription inhibitor (NNRTI), and is therefore commonly known as combination therapy. Combination therapy suppresses the virus and maintains the person's immunity as far as possible. It is generally thought to be the most effective treatment for HIV and AIDS.

Kerala

The health care system in Kerala consists of public, private, and traditional or alternate systems of health care. According to Kerala Government (2003) figures, there are 1281 allopathic, 113 ayurvedic, and 31 homeopathic state-run hospitals operating in Kerala. Some of these state-funded hospitals are equipped to test and treat patients with HIV and AIDS. However, the treatment available is limited to treating of symptomatic conditions of HIV and AIDS-related illnesses. At the time of the study, combination therapy was not yet available. Some of these hospitals also have units for HIV/AIDS counselling; however, the researcher's field experience revealed that these were far and few between, with a limited functioning. The level of medical care provided by the state-run hospitals is the one most commonly experienced by a significant number of HIV-positive persons and their carers.

Diagnosis and treatment of HIV- and AIDS-related conditions is also available in some private hospitals, where individual patients pay for medical care. The cost of medical care in these hospitals is generally very high for the average person in Kerala. Combination therapy is expensive (in the range of £250 per month) for those select few who can afford it, but still remains prohibitive for the majority of persons living with HIV/AIDS in Kerala.

In Kerala, the traditional or alternate systems of health care form an important segment in terms of "resort seeking", especially in the case of chronic, acute, and terminal illnesses such as HIV and AIDS. Often, this is the only means of treatment that is affordable to families of persons with HIV/AIDS, and they will resort to these systems to obtain treatment for the symptoms associated with HIV and AIDS.

Scotland

The health care system in Scotland is provided through the NHS, which was set up in 1948 to provide health care for all citizens, based on need and not on their ability to pay. It is made up of a wide range of health professionals, support workers, and organisations. It aims to deliver the highest level of physical and mental health for all citizens, within the resources available, by promoting health and preventing ill-health, diagnosing and treating injury and disease, and caring for those with a long-term illness and disability (National Health Service, 2003).

The treatment of HIV and AIDS is provided by the NHS, and includes treatment to suppress the virus as well as treatment of conditions resulting from the virus. Most treatment is given by specialists in HIV or genito-urinary medicine (GUM) clinics, although increasingly general practitioners are involved in the care of people living with HIV/AIDS. Both combination therapy (for person's whose immune system is reaching dangerously low levels) and anti-HIV drugs (often called anti-retroviral drugs), which are given in combination, are provided by the NHS.

Health care for persons with HIV/AIDS has inevitably been transformed since the late 1990's by the emergence of antiretroviral medication. The state-funded medical care and support available through the NHS, along with the opportunity of receiving free combination therapies and other treatment, is likely to have a beneficial effect on the quality of life of the person living with HIV and AIDS and their carers. However, as a result of the development of new drug therapies and of efforts to reduce escalating financial costs to the government, hospital inpatient care has decreased since the beginning of the epidemic. This has led to a greater utilization of outpatient services and community-based care and resources (Shaw-Taylor & Andrulis, 1997), thus adding to the burdens of the carer.

Services for HIV/AIDS

HIV-positive persons and their families, irrespective of which developmental context they belong to, have the right to competent, compassionate, quality health care and social services. Article 19 of the UN Declaration of Commitment on HIV/AIDS, adopted in the General Assembly Special Session on AIDS (UNAIDS, 2001b) recognizes this and reiterates,

> ***...care, support and treatment can contribute to effective prevention through increased acceptance of voluntary and confidential counselling and testing, and by keeping people living with HIV/AIDS and vulnerable groups in close contact with health-care systems and facilitating their access to information, counselling and preventive supplies (p.1)***

This section briefly looks at the varied services in the area of HIV/AIDS available in the two contexts.

Kerala

Kerala has HIV/AIDS monitoring groups in all of its 14 districts, with the headquarters situated in Thiruvananthapuram. Additionally, it has an HIV/AIDS Control Society, with a team of doctors and social workers, as well as 36 campaign and intervention projects operating in the state (Newton, 2001). However, none of these projects or units has any provisions in place specifically for those who care for family members living with HIV/AIDS.

Until 1992, HIV/AIDS remained largely unrecognised as a public health threat in India. Despite some domestic outcry that HIV was not a major issue in the country, the National AIDS Control Project, supported by a $100 million interest-free World Bank Group credit approved in 1992, became the first self-standing project in India to develop a national HIV/AIDS public health program (World Bank, 2003).

Policy discussions between the World Bank and the government encouraged the reversal of discriminatory public health regulations and the adoption of internationally agreed-on policies for the humane treatment of persons affected with HIV/AIDS. Pursuing internationally recognized ethical standards under the project responded not only to policy correctness as a principle, but was an essential pre-requisite for an effective policy in the prevention and control of AIDS, reducing the risk that infected persons would avoid medical help, and creating a favourable environment to promote disease prevention and control (UNGASS/World Bank, 2002).

Scotland

Over the past three decades several formalised services for HIV/AIDS have developed in Scotland. These include government departments, such as the Health Education Board for Scotland (HEBS) and the Public Health Institute of Scotland (which merged in 2003 to become NHS Health Scotland) and HIV/AIDS policy and/or campaigning organisations such as Waverley Care, which promotes the welfare of persons living with HIV/AIDS as well as that of their relatives, carers, and dependants. There are also HIV/AIDS-related research organisations, such as the Central Research Unit (CRU) of the Scottish Executive, which provides a research service principally in relation to social policy. Finally, phone and online help lines and voluntary organisations have also worked to fill the gaps in services.

Formal and Informal Support Systems

Social support networks are an important buffer for family carers. A social network is a specific set of linkages among a defined set of individuals (Mitchell, 1969). They can be seen as patterns or webs of social relationships that are critical in providing support to persons. How an individual lives depends much on how that individual is tied into the larger web of social connections (Freeman, 2002). Social networks enable an understanding of the linkages that exist between different institutional spheres and between different social groups (Srinivas & Beteille, 1964).

The care and support that carers receive, in both developed and developing nations, is especially significant because of the heavy burden that HIV/AIDS places on them. Both formal and informal support systems are equally significant in supporting family carers and enhancing the quality of their lives.

Formal Support Systems

Despite the fact that there are large numbers of HIV/AIDS-positive persons in Kerala, there is not a single organisation for the welfare or support of carers. The Kerala State AIDS Cell, the watchdog for HIV/AIDS-related issues, estimated that in the year 2001, there were approximately 70,000 people living with HIV/AIDS (Newton, 2001). They emphasize that this number is a mere approximation that is not based on any scientific survey, because definitive statistics relating to HIV/AIDS in Kerala are difficult to come by. The availability of any sort of support to carers is conspicuous by its absence and reflects a lack of awareness about the needs of family carers of persons with HIV/AIDS, a lack of political will, and/or a limitation of resources.

During the process of fieldwork, the researcher discovered two hospices that provided palliative care and refuge to persons who were dying of AIDS. These hospices provided support to the carers at a critical point in their caregiving. Personal communication with the Director of one of these hospices revealed that the hospice faced great financial difficulties as well as opposition from people in the neighbourhood. According to a leading Indian national newspaper ("Tackle Ignorance," 2003) a number of hospices for persons with HIV/AIDS have been forced to shut down or move under pressure by the residents of their neighbourhoods.

On the other hand, in Scotland, a number of formal social services are in place for carers of HIV positive persons. These include both statutory and voluntary services.

Additionally, carers can receive monetary assistance in the form of a Carers Allowance from the Government's Department of Work and Pension. They can also seek Direct Payment, that is, money that is given to the carer by the social work department to buy the support that the cared-for person requires. Carers can seek to arrange respite and domiciliary care through the statutory social services, which offers carers some relief from their daily care giving routines.

Additionally carers can seek support and counselling facilities from the NHS and from voluntary organisations that run buddy and phone help lines. The HIV-AIDS Carers & Family Support Group (Glasgow) provides practical and emotional support to carers, families, partners, and friends of individuals living with HIV or AIDS. Carers UK, a carer's organisation at the national level, provides online and phone helpline services.

Informal Support Systems

With limited formal support options, carers in Kerala have to rely on informal social support networks. However, this support can be fraught with anxiety and fear due to the stigmatising nature of HIV/AIDS. Carers' informal support networks are generally composed of extended family or relatives and friends, and at times include religious institutions. Carers in Scotland rely on similar informal support from family and friends.

Statutory Provisions for Carers

Caregiving is an international phenomenon. No nation is without family carers (National Alliance for Caregiving, 2004). However, the statutory provisions available in different countries can vary considerably. Statutory provisions consist of various laws or statutes enacted by the government and upheld by the judiciary for promoting and maintaining the objectives these statutes are meant to fulfil. These provisions can make it mandatory for statutory bodies to provide support when it is sought by an individual, thus providing legal redress when an individual's statutory rights are not met.

Statutory protections can be crucial for persons living with HIV/AIDS and their carers. They provide a means to seek assistance when stigmatisation or other factors (such as limited resources or corruption) combine to deny fundamental rights to persons with HIV and their families. These statutory provisions can serve as an important "safety net" for vulnerable individuals.

Kerala

Much of the development in today's India began with the introduction of Five Year Plans, launched in April 1951. These Plans initiated a process of planned economic development of the country—aiming not merely at raising the standard of living of the people, but also at opening new opportunities for a richer and a more varied life. One of the salient features of these plans was that they placed great emphasis on growth, justice, and social welfare in India, although the actual translation of these policies into reality more often fell short of expectations. This process is evident in the case of guidelines issued in regard to HIV/AIDS. Broad policy guidelines have been issued by the central and state governments in relation to treatment and care of persons living with HIV/AIDS. However, these guidelines do not hold any statutory powers. Moreover, there are no guidelines or statutes for the welfare of carers either at the state or national level.

Although HIV/AIDS was first reported in India in the mid 1980's, little attention was given to this development by the central or state governments. It was only recognised as a major health problem towards the early part of the 1990's. In 1992, the Indian Ministry of Health and Family Welfare launched a Five-Year Strategic Plan for HIV/AIDS prevention through the National AIDS Control (NACO) project. It allocated about $100 million for this project in the Eighth Five-Year (1992-97) plan for health. This amount comprised more than 15 percent of the nation's health budget, putting HIV/AIDS second only to malaria. However, there was no specific mention or data in relation to family carers of persons living with HIV/AIDS. So too, the Ninth (1997-02) and Tenth (2002-07) Five-Year Plans did not make any specific mention of carers of persons with HIV/AIDS, although, the Tenth Plan mentions that "sustained multi-sectoral efforts are needed to contain the infection, and combat the adverse consequences on the affected person, family, community and the country" (Government of India Planning Commission, 2003, p.113).

The First National HIV/AIDS Control Project aimed to provide low-cost treatment for people living with HIV/AIDS and funding for home-based and community-based care, including increasing the availability of cost-effective interventions for common opportunistic infections such as tuberculosis. It also aimed to fund new support services for care of AIDS patients in partnership with non-governmental organizations (NGOs) and community organizations such as small community-care hospitals, hospice programs, drop-in centres, support groups, and home-based care. Although it aimed to provide care for persons with HIV/AIDS, it did not make any provisions for their carers. Similarly, the Second National HIV/AIDS Control Project (1999-2004) mentions AIDS care only. Additionally, it points to the promotion of low-cost community-based care without stigmatisation for those living with HIV and AIDS (UNGASS/World Bank, 2002). However, here too, there are no provisions made for carers.

Scotland

While little or no attention has been paid to the problems of carers in India, the situation is quite different in Scotland. Here the concerns of those who provide care have been the topic of much deliberation and policy-making, and there is an existing set of policies and structures that recognises the contributions of carers.

Many of the statutory provisions that are in force in Scotland are enacted for the whole of the United Kingdom, where much of the legislation in relation to caregiving and carers falls under the purview of "community care". The policy of enacting various community care plans and programmes began with the 1959 Mental Health Act and has continued to the present day. A brief history of the development of policies related to family carers will illustrate the extent to which the phenomenon of family caring is recognised and understood in Scotland.

The UK Government White Paper, *Caring for People* ("Caring for People," 1989) states that:

> *Community care means providing the services and support which people who are affected by problems of ageing, mental illness, mental handicap or physical or sensory disability need to be able to live as independently as possible in their own homes, or in homely settings in the community. The Government is firmly committed to a policy of community care which enables people to achieve their full potential. (p.3)*

The development of a coherent and effective community care policy and practice has eluded successive governments and numerous official UK bodies have documented the chief obstacles. The Audit Commission report, *Making a Reality of Community Care*, recommended immediate action to channel resources into community care, as the social security bill for private residential homes exceeded £500 million. This report led to a review of community care policy by the government's health advisor, Sir Roy Griffiths. The Griffiths Report and the Government's response to it, *Community Care: Agenda for Action*, became the foundations for the White Paper, *Caring for People: Community Care in the Next Decade and Beyond* ("Caring for People", 1989). Following this, the National Health Service and Community Care Act of 1990 became a reality. However, the Government announced in 1990 that the changes would be implemented in stages, and in effect no extra money would be available until 1993.

One of Griffith's main concerns was that community care was "everybody's distant relative and nobody's baby". He saw the importance of having someone in charge and suggested that the responsibility for community care should rest with the local authorities and more specifically, with Social Services Departments.

The UK Carers National Association (CNA), which represents the needs of carers and brings them to the government's attention, did not believe that the new arrangements would transform the lives of carers; however, they did see it as a positive development, that would provide a better framework that would consider the needs and voices of carers, and would recognise the fact that "Carers are Community Care" (Pitkeathley, 1989).

The delays in the implementation of the Act announced in 1990 and termed as "phasing in" by the government came as a blow to the CNA and others who had campaigned on behalf of the carers to get them a better deal. Carers were unhappy, especially in the light of the expectations raised by the publication of the Social Services Committee Fifth report, *Community Care: Carers* (1990) (House of Commons Social Services Committee,1990).

This report was very much in support of the carers and came as a boost to all those concerned with their plight:

> *For too long carers have been the unrecognised partners in our welfare system. Their services have been taken for granted. They have been regarded as a resource, but not as people with their own needs. With the greater dependence to be placed by Government upon care in the community it is time to bring carers into the mainstream of our health-care arrangements and to give them the recognition, which they deserve. That recognition will inevitably cost money, but it is long overdue* (Community Care: Carers 1990, p. xxx).

The report made a number of recommendations, including making information on statutory and voluntary services available to all carers, assessing carers' needs as well as those of the dependent, greatly expanding the government's definition of respite care, development of domiciliary support services, and, more importantly, making financial provision for carers around improved income maintenance, improved opportunities to combine work with caring, and improved availability of domestic and nursing services.

In April 1993, the new legislation on Community Care was implemented. This legislation was criticised for not visibly improving the circumstances of the carers. However, the picture is more complex than the mere failing of Social Service Departments in relation to carers' needs. Twigg and Atkin (1995) point out that the relationship between carers and services is complicated. Service providers face a number of tensions and dilemmas in relation to carers' needs, because carers are not clients and exist "off centre" to service provision, yet are significant in the determination of provision. Additionally, there is a tension between service providers' wish to support carers while at the same time maximising care to the cared-for person. Caring involves a relationship wherein the context of the carer and the cared-for cannot be seen independently of each other. Finally, caring is rooted in kinship relations, and this affects how the services, society, and the carers themselves assess their need for help.

Many of the provisions of the Community Care legislation focused mainly on the service users, and the needs and aspirations of the carers were given insignificant attention. This led to a series of publicity campaigns by carers' organisations at local and national levels, which compelled the government to look at the issues facing the carers. As a result, a new law, Carers (Recognition and Services) Act 1995 (Her Majesty's Stationery Office, 1995) was enacted, which came into force in 1996. According to the Act:

> *A carer is entitled, on request, to an assessment when a local authority carries out an assessment of the person being cared for in respect of community care services or services for children. The carer's assessment should be taken into account when the local authority is making decisions about services to be arranged for the user* (Her Majesty's Stationery Office, 1995).

Since 1996, carers of people being assessed under the NHS and Community Care Act had the right to an assessment of their ability to provide care. The practice guide recognised that some users with illnesses such as HIV/AIDS will have care needs that may vary over time and might present regular and substantial burdens for the carers. The Act was a modest measure that reflected the consensus that carers, who provide a large proportion of care on a regular basis, deserve to be assessed for their needs alongside that of the user. The 1996 measure did not provide any new funding or guarantee of direct support for carers beyond the right to assessment. It was a move forward in giving recognition; however, it left open wider questions about formalising support structures and processes for carers. For services, carers remained dependent on the policy and practice of individual local authorities.

The assessment is intended to cover both the carer's perception of the situation, relationship with the user, tasks undertaken, and need for help, and a focus on the carer themselves, which may include health, social contacts, other responsibilities, and their own strengths and ways of coping. The Act also provides for assessment of prospective carers, in cases, for instance, where a user is about to require care after discharge from hospital. Assessment will relate to ability to care and to continue to care, but will not automatically assume a willingness to continue, or to continue at the same level. The practice guide points out that practitioners need to be sensitive to relationships between users and carers and to some of the stresses and difficulties, as well as the benefits, of caring, and refers to possible counselling and mediation needs. These are important issues in the context of carers who are themselves living with HIV or AIDS. The guide also raises the issue of managing assessments to balance the interest in sharing the outcome of assessments and of confidentiality, and of the need for sensitivity to the particular circumstances and different lifestyles of carers. The Act includes provision for carers who may be children or young people under the age of 18. However, it excludes assessment for carer volunteers who provide care as part of their work for a voluntary organisation (or as paid employment) and provides for no additional resources for carer assessments.

In 1999 the Government of UK published its national strategy for carers, which was broadly based on the three aspects of information, support, and care, and provided extra funding that would enable carers to take a break from caring. Around the same time, The Programme for Government launched by the Scottish Executive announced that a Strategy for Carers would be introduced in Scotland in 2000.

This carers' strategy comprised a package of measures aimed at supporting the many carers in Scotland who look after sick, disabled, vulnerable, or frail relatives or friends. This was drawn up following consultation with several carers' organisations based in Scotland. The measures included the promotion of new and more flexible services for carers, including respite care at a local level; introducing national standards for such services; recognising the need for monitoring by the Scottish Executive of the performance of health and social services in supporting carers; the introduction of carers' legislation to allow carers' needs to be met more directly; the provision of better and more targeted information for carers at a national level; and attention to the specific needs of young carers. The carers' strategy stated that these priorities are to be met by promoting the development of services for carers, setting standards for carers and respite services, supporting carers' legislation, and providing better information for carers. This also involved promoting carer-friendly employment and involving the NHS in supporting carers. This was guaranteed through the Scottish Executive's Planning and Priorities Guidance for the NHS, which required Health Boards and Trusts to give appropriate recognition to the needs of carers and the decision of the Scottish Executive to monitor this response (Scottish Executive Central Research Unit, 2005).

Subsequently, with the development of the Scottish Parliament, a few significant policies have emerged in Scotland since 1999 which have a bearing on the carers. It must be noted however, that there are no specific references to carers of persons with HIV/AIDS.

The Community Care and Health (Scotland) Act of 2002 is a significant statutory provision, which embodies a group of provisions concerning carers. The Act enables carers of adults to ask for an assessment of their ability to provide care, regardless of whether an assessment is carried out of the needs of the cared-for person. It also requires certain information to be provided to carers by a local authority. Similarly section 12 enables the Scottish Ministers to require Health Boards to prepare and submit to them carers' information strategies.

Under this act, the free personal and nursing care was introduced in July 2002. The aspect of free nursing care ensures that the cared-for will receive free nursing care, irrespective of their age, in care homes, hospices or the community. This has a significant bearing on carers of family member living with HIV/AIDS.

The Scottish Executive's strategic agenda is to work across boundaries to improve health within the community, thus all health provisions would require to be built around the needs of those who use them. This would minimise the traditional boundaries that exist between the service providers and users. This policy highlights the "joined-up approach" so that the stress that persons experience in obtaining the care or the kind of support they need as a carer is primarily addressed (Chakrabarti, 2001).

Similarly, as a result of Scottish Executive's policy on Joint Futures, there exists improved partnership between NHS and the statutory agencies namely, Social Work and Housing in order to secure better outcomes for service users and their carers. This is facilitated through the use of Care Needs Assessment Programme (Carenap) that provides a person-based assessment framework within a shared interdisciplinary context (Scottish Executive, 2004). It is a needs assessment tool aimed at minimising repeated professional assessments and facilitating communication of both services users and their carers.

Finally, Bates (2002) notes the lack of importance given to the expertise of the voluntary sector in relation to community care and national policy. He stresses the need to consult with carers, to listen to carers, and to deliver high quality service that is based on the knowledge and expertise of the voluntary sector. This has particular meaning for the carers, since it allows the voices of the carers to be heard and points to the need to develop necessary relationships and to build-in the systems and processes for a joined-up-approach, working together through the patients' experience of health service.

Conclusion

This chapter looked at the relationship between HIV/AIDS and development. Further, it explored the social realities and HIV/AIDS care and services that existed in the two contexts of the study and discussed the effect of these backgrounds on the lives of carers of family member living with HIV/AIDS.

The chapter notes that the socio-economic, cultural, and developmental realities that existed in the two backgrounds varied significantly. The primary social realities of the carers in Kerala were poverty, lack of medical resources/testing facilities and technology, lack of and/or prohibitive costs of combination therapy, absence of social security, and inadequate formal social support networks. The key social realities of the carers in Scotland were the presence of a comparatively high standard of living, advancement in the fields of health care management, the emergence of general use of combination drug therapies, established social security measures, and availability of formal support networks, as well as formal recognition of the role of carers.

Although there were key differences, there were also similarities between the two settings. While the severities of the family burdens differ significantly, the onus for caring for a family member living with HIV/AIDS in both contexts is on the carers, because of lack of resources available in both contexts for the persons living with HIV/AIDS themselves. Thus an understanding of the carers' social and developmental context discussed in this chapter explores their background and how that background could affect their capacity to provide care and support to their family member living with HIV/AIDS.

The next chapter describes the research methodology used in the study and relates the researcher's experiences during data collection. This provides an understanding of the methodology utilised and a window to conducting an in-depth inquiry into the lives and experiences of the family carers of persons living with HIV/AIDS.

CHAPTER 4: METHODOLOGY

The previous chapter examined the social and developmental context of the two research settings in order to provide a deeper understanding of the social realities of the carers' backgrounds. This chapter describes the research methodology used in the study.

Overall Strategy

This section presents the overall strategy of the research methodology utilised in this research, articulates the objectives of the research, and describes its exploratory nature as well as its combined qualitative and quantitative approach. It also presents the philosophical perspective to the research, in which it examines the phenomenological approach and its ties to grounded theory. The second section describes the participants and the use of the cross national method. It then looks at the issues of sample size and sampling. The third section discusses the various instruments used in data collection: in-depth interviews, the Ways of Coping Questionnaire (WOC) (Folkman & Lazarus, 1985) the Mental Health Self Reporting Questionnaire (SRQ) (Beusenberg & Orley, 1994) and records of fieldwork experiences. The fourth section discusses the varied ethical issues that arose while studying the sensitive area of caring for a family member living with HIV/AIDS. The fifth section discusses the qualitative and quantitative elements of data analysis, and the chapter closes with a conclusion and points to the next chapter.

The broad objectives of this research were to study the varied caring experiences of family carers of persons with HIV/AIDS. These included physical experiences; emotional/affective experiences; experiences related to sexuality, reproduction and children (where the carer is a partner); experiences with financial issues; and social experiences. It also discusses the formal and informal support networks available to the carers.

The research also aimed to study the various ways of coping utilized by the carers while caring for a family member with HIV/AIDS. Finally, it aimed to study the mental health of the family carers with a view to developing an insight into the effect of caregiving on their mental health and emotional well-being.

Nature of the Study

The study was designed to gain an understanding of issues associated with caring for those with HIV/AIDS. The primary goal was to explore the relationships between the varied elements in this study: caring for a family member living with HIV/AIDS, strategies for coping, and effects on mental health, such that ideas are generated for more formalised study. There were no formal hypotheses, though there were implied assumptions which informed the direction of the research.

Taking into account the nature of the study, and the objectives and questions for this research, the utilisation of a combined qualitative-quantitative research design was considered the most appropriate. Using a combined method connects the study objectives and methodologies in the context of a single study and enables access to a more comprehensive range of information and experience (Casebeer & Verhoef, 1997). No previous studies were found that combined the aspects of caring, coping, and mental health in relation to providing care for family members with HIV/AIDS, and thus a relatively unique methodology was adopted. It must be noted that the major focus of this study is on the qualitative aspect, and the quantitative analyses are more peripheral and exploratory.

Qualitative Aspects

Qualitative research can be defined as research that produces descriptive data, which are based upon people's own spoken or written words or observable behaviour (Bouma & Atkinson, 1995; Sherman & Reid, 1994) but where the data are not numerical. Although there may be times when the data is quantified, with qualitative research the analysis as well as the data is qualitative (Bouma & Atkinson, 1995). In qualitative research, it is more appropriate to utilise the term *research strategy*, because of the emphasis it places on flexibility and development of a research strategy that is suitable to the research concern. The qualitative research strategy enables the researcher to plan, observe, discover, describe, compare, and analyse the characteristic attributes, themes, and underlying dimensions of a particular unit (Seaman, 1987). The essence of this approach is to view events, actions, norms, values, etc. through the perspective of the individuals who are being studied. It focuses on the questions: What do *they* think? How *they* view the world? (Bouma & Atkinson, 1995) and focuses on the meaning of the subject of the study, rather than on the frequency of the occurrence. Further, qualitative research is multi-method in its focus, and it involves an interpretive, naturalistic approach: studying things in their natural setting and trying to interpret phenomena in terms of the sense people make of it (Denzin & Lincoln, 1994) and doing this in a rigorous manner so that the findings can be trusted and be generalisable. The utilisation of qualitative research strategies enables the researcher to understand the nature of a person's experiences. It facilitates an understanding of what lies behind any phenomenon about which little is known or more is sought to be known (Bouma & Atkinson, 1995; Denzin & Lincoln, 1994).

The qualitative data in this study describe, explain, and characterize the experiences of the respondents who were family carers. This aspect of the study is relatively open-ended and exploratory, seeking to discover new information about the experiences of carers. The qualitative approach facilitated the researcher in understanding the carers' feelings and perspectives in their own words and encouraged an exploratory and descriptive analysis which stressed the importance of context, setting, and the respondents' frame of reference (Marshall & Rossman, 1995). Qualitative techniques are especially appropriate to build the body of knowledge in the area of family caring of HIV-positive persons, where little in the way of structured, quantitative information is available. Furthermore, no structured measurement instruments exist which are appropriate for tapping the information sought in this aspect of the study.

Quantitative Aspects

In contrast with the qualitative method discussed above, this approach classically focuses on producing data in a numerical form and then using statistical procedures to provide useful descriptions of the phenomena being studied and to test hypothesis. The research design will indicate how hypotheses will be tested, and verified or modified (Robson, 1997). Quantitative methods strive to test theories that explain phenomena by showing how they are derived from theoretical assumptions, reduce social reality to variables in the same manner as physical reality, and attempt to tightly control the variable in question to see how other variables are influenced.

Quantitative research designs include measurement, prediction, and causal inference, which may not fit in isolation with the world of social science, where perceptions, feelings, values, and participation are frequently the variables that the researchers are attempting to measure. Thus by omitting qualitative methods, the researcher may overlook many phenomena that occur within the context of the setting. Campbell and Fiske (1959) argue that a quantitative measurement rests on qualitative assumptions about which constructs are worth measuring and how constructs are conceptualized (Shaddish et al., 1991). Conversely, by omitting quantitative methods, causal relationships between variables as well as quantification and analysis of those variables to determine statistical probabilities of a particular outcome will be absent.

In the present study, a quantitative approach was used to evaluate relationships among coping, mental health, and various quantifiable aspects of the carers' experiences. Because of the small number of participants involved in the study, it was not possible to draw definitive conclusions about these relationships, but the data are presented as suggestions for further quantitative studies.

Benefits of Combining the Approaches

To overcome limitations in both qualitative and quantitative approaches, this research combined the two perspectives to develop a more comprehensive research design. The multimethod approach utilised in this research is supported by the founders of grounded theory (Glaser & Strauss, 1967). Moreover, because this study researches complex human experience, a multiple perspective that utilises both qualitative and quantitative designs is crucial in enabling reflection, understanding, and analysis of these complexities. Social scientists (Agar, 1997; McKeganey, 1995) have suggested that the emergence of HIV/AIDS has brought an increased openness for quantitative and qualitative researchers to work together to understand this complex, multifaceted phenomenon.

Duffy (1987) points out the varied benefits of combining the two perspectives. She suggests that whereas the quantitative perspective strives to control for bias so that facts can be understood in an objective way, the qualitative approach strives to understand the perspective of the person experiencing the phenomenon. Thus, the accumulation of facts and causes of behaviour are concerns of quantitative methodology, whereas, the changing and dynamic nature of reality is the concern of qualitative methodology. Moreover, Duffy stresses that both research designs seek reliable and valid results. The consistency of data is indicated by the researcher's ability to replicate the findings in the quantitative design, while validity of the qualitative findings are crucial so that data are representative of a true and full picture of constructs under study. By combining the two methods, the advantages of each method complement the other, resulting in a stronger research design that has valid and reliable findings; and limitations of the individual methods are minimized.

HIV/AIDS is a stigmatizing illness and affects the carers in different ways. Many of these effects are little known or understood; thus the qualitative exploration is most appropriate. At the same time, the process of caring for a family member living with HIV/AIDS involves multiple stresses, and individual carers could use a variety of known strategies for coping. Thus the present research aimed to study these ways of coping from a quantitative perspective, so that the experiences of the carers could be validated and compared to coping experiences associated with other forms of stress. Similarly, caring for a family member with HIV/AIDS makes the carer vulnerable: physically, emotionally, and socially. This inevitably affects their mental health and emotional well being. Hence, through the use of SRQ, the research attempted to study the impact of caring for a family member living with HIV/AIDS on the mental health of the carers. The study thus weaves the qualitative data on experiences with the quantitative data that is obtained from the WOC Scale and the SRQ, such that the combination of the qualitative and quantitative methods are complementary and facilitate a more comprehensive, valid, and reliable outcome.

Philosophical Approach

A philosophical perspective is implicit in any research project, because research is directly linked to the assumptions commonly accepted concerning ontology, epistemology, and human nature (Morgan & Smircich, 1980). All qualitative researchers are philosophers who are guided by abstract principles (Denzin & Lincoln, 1994) that shape the researcher's worldview: theory, method, analysis, and the actions taken in it. In this study, articulating a philosophical perspective enabled the researcher to build clarity and rigour that was necessary to interpret the social world of the carers.

A constructivist paradigm (Denzin & Lincoln, 1994) was viewed as an appropriate philosophical approach for this research, as it was in keeping with the focus of the study, namely the life experiences and lived realities of the carers. Adopting a constructivist epistemology of knowledge provided the researcher with the understanding and conviction that the carers were the experts on their own lives. Further, a phenomenological perspective was considered an appropriate philosophical basis of the research. Thus, the researcher drew from the literature of phenomenology in the present study.

Bergum (1989) defines phenomenological research as a method that "explores the humanness of being in the world, is a drama, an interactive involvement of both the 'researcher' and the 'researched'" (p.55). She suggests that the fundamental concern of this approach is with the understanding of the meaning of life through interpretation of human experience. Phenomenologists use themselves to obtain an understanding of the respondents, by intensively interviewing a small number of persons.

This research seeks to develop an understanding of the meaning of the phenomenon of caring for a family member living with HIV/AIDS. By viewing the research through the phenomenological perspective, insight has been gained into the phenomenon of caring for a family member living with HIV/AIDS, from the perspective of the carers themselves. It was important to approach this topic from the experience of the carers, using their words and voices, in order to capture the full meaning of the experience of caring for their loved ones with HIV/AIDS, which consumed so much of their energy and became inextricably woven into their consciousness.

Because of the many negative value judgements that have been associated with HIV/AIDS, persons with HIV/AIDS and their family members have had little opportunity to speak openly about their experiences, for fear of stigmatisation and rejection. Thus much of their experience remains little known or understood. Adopting a phenomenological approach allowed the researcher to shed light on the experience of family carers and honour their experience, while avoiding assumptions and preconceptions that might have misconstrued the meaning and significance of experience for the carers.

Grounded Theory

In this study, the researcher utilised some elements of the grounded theory approach, although it should be emphasized that this study is not exclusively based on grounded theory methods. Grounded theory is a form of qualitative research initially developed by Glaser and Strauss (1967), which later evolved over time and was further developed by Strauss and Corbin (1990). This method ties in well with the phenomenological approach. Grounded theorists, like phenomenologists, share the aim of describing complex human experience in its context, with an emphasis on describing the day to day occurrences in the lives of persons, using their own words (Lipson, 1989). However, the theoretical underpinnings of the two methods are different. Whereas grounded theory has been derived from a sociological tradition, phenomenology has been derived from a philosophical tradition.

The grounded theory method is of particular significance in the field of social work research. Gilgun (1994) suggests that qualitative approaches such as grounded theory have a "hand into glove" fit with social work practice. Wells (1995) and Miller and Fredericks (1999) point out that grounded theory has been and continues to be the research methodology of choice in qualitatively oriented research fields within social work, medicine, nursing, and education.

Grounded theory is an important research strategy for the study of HIV caregiving, because it is able to explore the richness and the diversity of human experiences (Streubert & Carpenter, 1995) such that new ideas and theories are generated to aid further research and practice (Padget, 1998). Grounded theory is most accurately described as a research method in which the theory is developed from the data, rather than the other way around. This is thus an inductive approach, that is, it moves from the specific to the more general. The method of study is essentially based on three elements: concepts, categories, and propositions, or what were originally called "hypotheses". However, concepts are the key elements of analysis, since the theory is developed from the conceptualization of data, rather than from the actual data. In grounded theory, data collection and theory generation are considered as two parts of the one process (Glaser & Strauss 1967).

Grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) is a method concerned with the generation, elaboration, and validation of social science theory; so that the accepted canons for doing good science, such as consistency, reproducibility, and generalizability, are fulfilled, although they are not to be understood in a positivist sense. The general goal of grounded theory research is to construct theories in order to understand phenomena. Thus, a grounded theory is one that is inductively derived from data, subjected to theoretical elaboration, and judged adequate to its domain with respect to a number of evaluative criteria. This approach is best regarded as a general theory of scientific method concerned with the detection and explanation of social phenomena. To this end, grounded theory is reconstructed as a problem-oriented endeavour in which theories are generated from robust data patterns, elaborated through the construction of plausible models, and justified in terms of their explanatory coherence.

Glaser and Strauss (1967) posit that grounded theory emerges inductively from its data source in accordance with the method of "constant comparison", which is an amalgam of systematic coding, data analysis, and theoretical sampling procedures that enable the researcher to make interpretive sense of much of the diverse patterning in the data by developing theoretical ideas at a higher level of abstraction than the initial data descriptions.

Thus a constructivist paradigm (Denzin & Lincoln, 1994), along with elements of the phenomenological and grounded theory method (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was found to be appropriate for this study, because together, they provide a perspective through which the qualitative aspects of the study could be developed, as well as a foundation for data collection and analysis.

Grounded theory research begins by focusing on an area of study and gathers data from a variety of sources, including interviews and field observations. As the aim of grounded theory is to generate rather than test theories, the analysis begins shortly after the researcher commences the data collection. Transcripts of tape recorded interviews and conversations, field notes, and other written materials provide raw data. Once gathered, the data are analyzed using coding and theoretical sampling procedures. When this is done, theories are generated, with the help of interpretive procedures, before being finally written up and presented, which is an integral part of the research process. Different authors have interpreted grounded theory in varied ways, even to the point that there is a disagreement among the original authors, Barney Glaser and Anselm Strauss (Bartlett & Payne, 1997).

The basic framework used for analysis in this study is in keeping with the stages of analysis as described by Glaser and Strauss (1967) and Strauss and Corbin (1990). It is important to stress that the researcher followed the broad parameters of grounded theory based on his interpretation of their work rather than adhering to the specifics of each stage.

The initial stage of a grounded theory study consists of data collection and development of categories to describe the data. As grounded theory is a tool for qualitative investigation, the commonly referenced forms of data collection are field studies, participant observation, and semi-structured interviews. A full transcription of the data is followed by the development of categories by open coding of the transcripts. The next stage consists of saturation of categories in which examples of categories are collected; the researcher proceeds through the transcripts until no new categories emerge from the data, ensuring consistency, regularity and leaving no loose ends.

The stage that follows consists of definition of categories, that is, once the categories have been saturated, formal definitions are developed, enabling each category to be compared and contrasted to other categories. This leads to theoretical sampling, wherein the researcher develops theoretically relevant categories further from the categories that emerged from the first sample of data. This stage is followed by axial coding, that is, the development and testing of relationships between categories. Next, a stage of linking with existing theory or theoretical integration follows, where emerging theory is linked with existing theoretical constructs. The final stage consists of grounding the theory, or testing of the emerging theory, by returning to the data and validating it against actual segments of text. This is known as the constant comparison of the data.

In this study, the researcher deviated from the original derivation of grounded theory (Glaser & Strauss 1967), which focused critically on the generation of theory from data without reference to the researcher's prior knowledge of the phenomena under investigation. However, the researcher in this study did possess a prior understanding and knowledge of the field being studied. The researcher also departed from the steps or stages delineated above, in that not all stages were included. In particular, the researcher did not utilise formalised axial coding in this study as it was felt that, given the research intentions outlined above, this would not add meaningfully to the findings nor would it threaten their validity.

Participants

Cross-national Method – Kerala and Scotland

HIV/AIDS has spread throughout the world's population, on every continent of the world (Bharat et.al, 2001). It is a complex, global pandemic that respects no geographical boundaries (Gould, 1993). In order to explore the influences of context on the experience of family caring in HIV/AIDS, the study was set in two contexts of development: Kerala and Scotland. The goal was to develop a deeper insight into the area of family caregiving of persons with HIV/AIDS, across the two contexts. It is not the primary aim of this study to make comparisons between the two contexts, which are arguably not comparable. Rather, the study aims to extend and deepen the understanding of the phenomena by bringing in data from two very different settings, thus increasing the likelihood of discovering relationships and issues that have previously been unexplored. It does not aim to gain evidence of the similarities and differences in the two contexts, however inevitably these are discussed with the aim, as stated above, of enhancing an understanding in relation to the issues of caring and the experiences of family carers. Researching the subject in two different contexts has provided the study with two distinct cultural perspectives on the experiences of family carers of persons with HIV/AIDS, one from a developing nation with a strong traditional culture, and one from a developed nation with a more modern culture.

As Oyen (1990) observes, cross national studies are not easy and straightforward. However, she argues that despite the problems, more than ever before, cross-national studies are being carried out, and, there is both a need and demand for comparisons across countries. She cites two major factors responsible for this: growing internationalisation and the globalisation of problems, and, argues that the globalisation of problems lends itself to a cross-national approach.

With the phenomenon of globalisation and growing internationalisation, more people cross national borders, exporting and importing social and cultural manifestations.

This has led to the establishment of international organisations that foster a global understanding of problems and intervention into these problems. This is especially relevant in the case of HIV/AIDS, which is readily capable of crossing national and cultural boundaries. A cross-national perspective that extends its understanding of the life experiences of family carers of positive persons across two cultures provides a broader and deeper insight into the realities of this epidemic.

Sampling

Sampling is the process by which participants in a study are chosen from the larger population (Seaman, 1987). Given the nature of the research concern, a purposive sampling technique was utilised, as the sample required were selected on the basis of some defining characteristics, rather than being representative of a particular population. Purposive sampling involves the conscious selection by the researcher of certain subjects or elements to include in the study (Burns & Grove 1987). Moreover, in grounded theory, the initial sample is drawn from those who are most likely to have experienced the phenomena under study (Glaser & Strauss 1967).

In order to gain a deeper understanding of the varied issues in caring, the researcher made sure that at the time of the interview, the carers were caring for a family member living with HIV/AIDS and that there was no other major illness in the family that might cloud their caring experiences. Moreover, it was necessary that the carer was residing with the cared-for person or maintained direct contact.

In Kerala, 23 carers of family members living with HIV or AIDS were interviewed. This number was reached by a process of theoretical saturation. That is, during the process of data collection, the researcher came to a stage where no new qualitative information was emerging from the interviews with the carers; rather he was getting more confirmation about the varied aspects of the study. This method of sampling is in compliance with the methodology of grounded theory (Glaser & Strauss, 1967). It must be noted that generally quantitative studies use a much larger sample size than was used in this study. Nonetheless in this study the above sample size was adequate in gathering quantitative data using the WOC (Folkman & Lazarus, 1985) and the SRQ (Beusenberg & Orley, 1994), because it produced meaningful data.

In the case of Scotland, the sample consisted of five carers: two from Glasgow and three from Edinburgh. The sample size from the two contexts varied so considerably because of the practical difficulties in obtaining respondents in Scotland. This will be discussed later in the section on practical constraints. It is important to note that the researcher was unable to achieve theoretical saturation of the qualitative data, nor was he able to get an adequate sample size for the quantitative scales. The small Scottish sample, does however limit the capacity of this research to generalise the findings to a wider context. It is crucial therefore to emphasise that greater caution should be exercised when relating the findings of this study to a larger population. This may be considered as a limitation of the study, nonetheless it also provided a meaningful and vital dimension to this study, which can be seen as illuminating and providing a benchmark for further similar studies.

Data Collection

Development of the Research Tools

The research tools comprised three research instruments: an Interview Guide; a Ways of Coping Scale (Folkman & Lazarus, 1985) and the Self Reporting Questionnaire (Beusenberg & Orley, 1994). These instruments are discussed more fully in the sections below.

Interview Guide

For the qualitative aspects of the study, an interview guide (Barlett & Payne, 1997) was developed based on information available from the existing literature and from discussions with professionals in the field. In qualitative research, especially when using grounded theory, it is debated whether a literature review should be considered before commencing the field study. The researcher adopted Streubert and Carpenter's (1995) view, that in order to focus the study, a cursory review is necessary.

The guide consisted of open ended questions. These questions are flexible and allow the interviewer to probe deeper into issues and clear any misunderstanding that may exist. They also aid the interviewer to make a clearer assessment of what the respondent is actually trying to say. Finally, open-ended questions may result in unexpected or unanticipated answers, which may suggest hitherto unthought-of areas and relationships (Cohen & Manion, 1989). Marshall and Rossman (1989) refer to the role of intuition in qualitative research, which should not be underestimated. They suggest that questions should be related to intuitive hypotheses or hunches.

The Interview Guide, as the name suggests, was used more as a tool for the researcher to lead the discussion with the carers. The questions were grouped under a number of headings to ensure that all aspects were covered, though in reality the respondents were free to narrate their experiences and stories as they emerged in their minds. The aspects covered in the guide consisted of the varied issues involved in caring, such as physical aspects of caring, emotional experience as a carer, social aspects of caring, financial aspect of caring, matters relating to fear of infection and reproduction, matters relating to children, and formal and informal support networks. A copy of the Interview Guide is provided in Appendix D.

Ways of Coping Scale

A modified version of the Revised Ways of Coping (WOC) scale (Folkman et al., 1986) was used in order to study the coping strategies used by the participants. The WOC is an 85-item questionnaire containing a wide range of thoughts and acts that people use to deal with the internal and/or external demands of specific stressful encounters. The list provides some of the commonly used ways of handling stress and reducing distress. Usually the encounter is described by the subject in an interview or in a brief written description, saying who was involved, where it took place and what happened. Sometimes a particular encounter is selected by the investigator as the focus of the questionnaire.

This scale was initially developed by Folkman and Lazarus (1985), with 66 items representing a wide range of stressful situations. The scale was then used in a study of a wide range of stressful encounters reported by a community sample of middle-aged married couples (Folkman et al., 1986) to establish its reliability and validity.

For the current study, this scale was modified with a few additions by the researcher. An additional 19 items were added in order to capture coping strategies that might be more appropriate for respondents in the contexts of Kerala and Scotland. This brought the total number of items to 85. The response format was also simplified. Instead of using a Likert scale with several possible responses for each item, a simpler Yes-No response format was used. This modification was made in order to streamline the administration of the scale during face-to-face interviews, where the process of describing several possible responses to each item would have become laborious. Each item was given a score of 1 if the respondent indicated that he or she had used that coping strategy, and a score of 0 if the strategy was not used. The items were grouped into nine subscales. The grouping was made on a rational basis that reflected the original groupings made by Folkman et al (1986) but also considered the sense/essence of the additional items. The practice of adding items to the standard form of the WOC is in keeping with the recommendations of the authors of the scale, who encourage researchers to adapt the scale to reflect specific study contexts (Folkman et al., 1986).

In order to get some idea of the reliability of the nine scales, internal consistency coefficients (Cronbach's alpha) were computed for each of the nine scales. These are reported in Table 1. It can be seen that the internal consistency of the nine scales varied considerably, from an extremely low internal consistency coefficient of .01 for the Distancing/Detachment scale to a modestly high coefficient of .68 for the Seeking Social Support scale. These scores may be disappointing from a pure psychometric perspective; however, they reflect prior experience with the WOC, (Schwarzer & Schwarzer, 1996) and they are consistent with the theoretical understanding of the coping process. As Schwarzer and Schwarzer (1996) note, internal consistency may not be expected or desirable when the goal is to measure real-life coping efforts. The complexity of stressful events and the efforts to cope with them may lead to individual and situational variability that works against consistent measurement. It should be noted that more research would be necessary in order to further investigate the reliability and validity of the Ways of Coping Questionnaire before this instrument could be used routinely to assess coping patterns in family carers of persons with HIV/AIDS universally. A copy of the revised WOC can be found in Appendix E.

Table 1

Internal consistency for the WOC scales

Scale	Internal Consistency
Problem Focused Coping	.54
Positive Reappraisal	.50
Accepting Responsibility	.30
Seeking Social Support	.68
Self Controlling	.46
Tension Reduction	.21
Self Blame	.63
Distancing/Detachment	.01
Escape/Avoidance	.02

Using the WOC represented something of a departure from the qualitative nature of the overall study. This instrument was included in the data collection procedure in order to allow further exploration of the phenomenon of coping in the context of caring for a family member with HIV/AIDS. The WOC represents a fairly comprehensive measure of the broad spectrum of possible coping behaviours, and it was felt that questioning the respondents about such a wide array of possible coping strategies might uncover approaches that they were using but were not so aware of. It was intended to supplement the open-ended questions included in the Interview Guide, and it also allowed for some exploratory quantitative analyses which will be described later. These analyses did produce some interesting results, which will be discussed in the results chapter. Thus, the addition of the WOC to the data collection package seems to have been useful.

Self Reporting Questionnaire

The Self Reporting Questionnaire (SRQ) was originally developed as a screening instrument to assess the level of non-psychotic mental health problems in various populations around the world (Beusenberg & Orley, 1994). It consists of 20 items that describe psychiatric symptoms, and the respondent is asked to indicate whether he or she has experienced each of the symptoms within the past month.

Translated versions of the SRQ have been used in over 30 studies around the world, particularly in developing countries. Various studies have established that the SRQ has adequate reliability and validity, and is appropriate for use in either self-administered or interview contexts (Beusenberg & Orley, 1994).

The development of SRQ has led to its use as a screening and case-finding instrument in primary care settings as well as research in psychiatric clinics in different cultural settings. Each of the 20 items is scored 1 or 0. A score of 1 indicates that the symptom was present during the past month; a score of 0 indicates that it was absent. In order to assess reliability of the SRQ, internal consistency (Cronbach's alpha) was computed for the total scale, yielding a coefficient of .88. This suggests that the participants responded to the scale in a consistent manner, and also suggests that the SRQ provided a fairly generalized indicator of overall distress in this study. A copy of the revised SRQ can be found in Appendix F.

Piloting

The interview guide was piloted in both the research contexts. One interview was conducted in Scotland and two interviews were conducted in Kerala. The revised WOC scale and the SRQ were also piloted alongside the qualitative interview guide. Piloting the tools increases the credibility of a qualitative study and helps in the implementation of the study (Padgett, 1998). It is used as an experiment to test the future study, to find out if questions are confusing, irrelevant, or otherwise need to be changed. The purpose of the pilot was to uncover and modify problems with the interview protocol and to gain a deeper insight into the perspectives of carers. It was also used to test the clarity and the flow of questions and to rehearse the process of interviewing.

Through this exercise the researcher developed a deeper insight into the perspectives of the carers and was able to make minor modifications to the tools and also to arrange some of the questions more appropriately. Minor modifications and rewording were made to the WOC, while the SRQ, which had been field tested in a number of countries including India, was deemed to suit the field reality. Pilot testing also enabled the researcher to check for ambiguity and to gauge the duration the interviews would take.

Given the sensitive and demanding nature of the research, it was felt that it would be practical to pilot the tools with a restricted number of carers. Additionally, the potential carers group available for the research in Scotland was extremely small and difficult to access, so the number of pilot interviews was necessarily limited.

Fieldwork

The Settings

The fieldwork for the study was set in Kerala and Scotland. In Kerala, the data collection was carried out in 5 districts, which included Kasaragod, Kannur, Kozhikode, Thrissur and Ernakulam. In Scotland, data collection was carried out in Glasgow and Edinburgh.

Kerala

The main facilitating centre for data collection was the State Management Agency (SMA) based in Kozhikode (formerly known as Calicut). SMA was set up in July 1997 in collaboration with the Government of India (GOI), the Department for International Development (DfID) of the British Government and the State AIDS

CELL (SAC) to implement targeted intervention in the state of Kerala through non-governmental organisations (NGOs).

The role of SMA is to provide logistic support for targeted intervention by developing systems for supporting and managing projects. It supports NGOs from the various districts of Kerala in identifying areas of interventions, conducting needs assessment, developing proposals, and in implementing/monitoring and evaluating projects. SMA also provides technical and financial inputs. Thus the different NGOs from the above districts helped the researcher to liaise with carers, who became the respondents for this study.

The preparation for the fieldwork in Kerala began with the researcher meeting with the Project Co-ordinator of SMA. The researcher knew about SMA because of his personal contact with the Project Co-ordinator. This led to a series of meeting with the staff from the NGOs. These meetings helped explain the research and the context of fieldwork in Kerala. The researcher was assisted by the NGOs in arranging the interviews. The staff contacted the carer of each positive person to discuss the research and helped make arrangements for those carers who agreed to come to the agency.

Scotland

One of the organisations considered for fieldwork was based in Glasgow and worked primarily with carers of people with HIV and AIDS. The researcher contacted the agency and the initial response towards facilitating the interviews was very forthcoming. A meeting was set up between the researcher and the staff of the organisation, in which the study was discussed. The staff in turn agreed to liaise with the carers, with the aim to seek their voluntary participation in the research. This meeting was followed by a series of other meetings with agency staff. The researcher was asked to provide various documents in support of his work, for example letters from his university, stating that he was a bona fide student, and consent from the researcher to have a police check carried out on him.

During the months that followed, the agency assured the researcher of full and voluntary participation from carers. However, no confirmation for the interview process to commence was received. Subsequently in the passing months, the researcher contacted the agency again. He was once again asked to submit various documents relating to his personal credentials etc. This was followed by a part interview with an ex-carer (the data of which has not been used in this study). The researcher was getting anxious and contacted the agency again, only to be told of their inability to participate in the research process. The whole exercise took almost a year which resulted in no success. The researcher was thus compelled to widen the area of his search and contacted several other agencies in Glasgow, including statutory bodies, with no success. However, through an acquaintance in Glasgow, two carers were interviewed. The difficulties in accessing other carers in Glasgow led the researcher to contact two organisations in Edinburgh, Positive Voice and Solas, where he was able to conduct three interviews with carers. A brief description of these organisations is given below.

Positive Voice, Edinburgh. Positive Voice is a self-help organisation that endeavours to support the health and well being of persons living with HIV/AIDS, their partners, families, and carers, through the provision of peer support, communal advocacy, and individual advocacy.

Solas, Edinburgh. Solas (a Gaelic word for light and comfort), is a voluntary organisation that has offered support services, information, and an informal meeting place for positive persons since 1991. It is a part of the Waverley Care Trust, whose aim it is to promote the welfare of persons living with HIV/AIDS residing in the Lothians and to support their relatives, carers, and dependants. Solas provides psychosocial support and information services to positive people and their families and carers.

The Interview Process

In both the settings, the interviews began with the researcher introducing himself and the study. The content of the discussion is reflected in the letter of information (Appendix A). The researcher reassured each respondent that the information that they would provide would be kept confidential and that their names and addresses would not be quoted anywhere in the study. Moreover, they were assured that the information shared by them would be used only for research and educational purposes. The researcher also assured the respondents that they were free to refuse to answer any question they found uncomfortable or too personal, and were free to withdraw from the process at any point during the interview if they so desired. Care was taken to explain the significance of informed consent. The carers were then requested to sign the letter of informed consent (Appendix B) for their participation in the study.

Audio tapes were used during the interviews to record and store the interview that generated the qualitative data. Recording the interviews also ensured the free and smooth discussion during the interview, by freeing the researcher from the necessity of taking notes. There were several instances where interviews had to be stopped to answer and clarify questions raised by the carers in both contexts.

The WOC scale and the SRQ were administered as part of the interview process with each respondent in Kerala. The researcher translated each item and noted the carer's response as it was given. There were several practical reasons for using this procedure rather than having the carers respond to the questionnaires in writing. The carers did not read English, and even if the questionnaires were translated into Malayalam, for most carers it would have created an additional burden to read and complete the questionnaire. Furthermore, many of the carers would have been burdened by the necessity of travel (sometimes for a fair amount of time) to be able to return the questionnaires by post.

The WOC scale and SRQ were handed to each of the respondents in Scotland, and they were given the option of completing them at the time of the interview, or of doing so at a later point and returning them by mail to the researcher. A stamped self-addressed envelope was provided for this purpose. All carers, with the exception of one, preferred to take the questionnaires home and think about them before they completed them.

The procedures for completing the two questionnaires differed between the two contexts because of fundamental differences in the resources available to the carers in the two contexts. The carers in Kerala did not have the opportunities that one takes so much for granted in a developed world context: privacy to complete a form, ability to spend time for themselves, infrastructure such as post boxes in close vicinity, etc.

Another significant aspect of the interview process in the context of Kerala was the element of monetary restitution. As most of the respondents had to travel a considerable distance to attend the interview; the researcher was asked by the NGOs whether he would consider compensating the carers for their travel expenses. The researcher was pleased to consider this request and travel expenses for carers were paid.

In general, administering the interviews, along with the WOC scale and SRQ in Kerala lasted around three hours. There was one exception where the interview was carried out over two days. The details of this circumstance are discussed more fully in the section on fieldwork experiences. In Scotland each of the interviews lasted around two hours. Moreover, in Kerala, the duration of the interviews was at times lengthened, because there were instances where interviews had to be interrupted to answer and clarify doubts and questions raised by the carers. It emerged that the carers in Kerala felt a great need for adequate and reliable information on HIV/AIDS. This was in sharp contrast with the researcher's experience in Scotland, where some of the carers were actually offering the researcher insights into the HIV and AIDS scenario.

Fieldwork Experiences

The experiences that the researcher had during data collection are discussed with the view to provide the reader with a closer insight into the fieldwork process. The fieldwork experiences in the two contexts differed considerably, because the circumstances of the carers were so different.

Kerala

Most of the interviews were held in the NGO's office premise. This was to ensure maximum confidentiality to the respondents; however, two interviews were conducted at the homes of the carers. The experiences of the researcher in both cases were different and shed light on the reality of interviewing the carers of family members living with HIV/AIDS in Kerala. Thus both cases are discussed here.

As it was difficult for one of the carers to travel a long distance to the office, the researcher, along with a staff from the NGO, travelled to the residence of the carer. When they arrived at the home of the carer, the neighbours living close to their house also arrived, wanting to know the reason for the researcher's visit, and remained there until the researcher left. In Kerala, this custom of neighbours calling upon other neighbours, without being invited, is an accepted practice. However, this meant that the researcher had great difficulty to ensure confidentiality to the carer. Fears of disclosure and stigma also prevented a free atmosphere for this carer to share her experiences of caring for her son. Additionally she needed to interrupt the interview on three occasions to attend to the needs of her ailing son.

The second experience of conducting the interview at the home of the carer was particularly poignant, and highlights the ethical considerations and experiences of interviewing in areas of great sensitivity, such as family caregiving in the field of HIV/AIDS. In this case the carer lived in a village that was far away from the town. The respondent and her husband lived in close proximity to their neighbours, who knew nothing about her husband's advanced AIDS condition, except that he was very unwell. This may be attributed to the general lack of awareness about HIV/AIDS in the villages. The only support that the carer had was from the regular contact that she kept with the NGO.

The researcher was told that it would be devastating for the family if their HIV status was known in the village, because of its rather traditional and moralistic outlook. The family feared that disclosure would perhaps force them to flee from the neighbourhood, as such experiences have often been reported in the media. On the one hand, the carer could not manage to come to the agency for long periods of time leaving her husband alone, and on the other, the researcher arriving at her home presented a potential risk of disclosure. This situation presented a real dilemma for the researcher that is, balancing the potential risk to the respondent against the potential benefits of the interview. The NGO staff discussed this with the researcher, and it was felt that the visiting the carer during the late evening would resolve this situation. The staff discussed this option with the carer, who was more than willing to oblige.

The staff and the researcher travelled to the carer's house after night fell and held the interview at her home after 10 o'clock in the evening. The last part of the journey to the carer's house was taken on foot to ensure that the neighbours were not alerted by the sound of a motorbike. It was very dark and most of the neighbourhood appeared to be asleep. This was the only way to guarantee confidentiality and protect the family from any potential risk of disclosure.

There was another instance, as mentioned above, where the interview had to be carried out over two days. This was because of the intense pain the carer experienced during the process of the interview. Her experiences catalogued the misery and pain visited upon family members of persons living with HIV/AIDS. She said that narrating her experiences was too unbearable, because she felt she was reliving all the pain she had lived through during the early part of her husband's diagnosis. She recalled the harsh reactions from her husband's and her own family, the stigmatisation she underwent while giving birth to her child from the hospital staff including the doctor, her being quarantined under suspicion of being positive for HIV, the rejection by friends and relatives, and the negative responses from her neighbourhood that finally forced her and her family to flee from their own home.

Scotland

The interviews in Glasgow were conducted in the carers' residences. Two of the interviews in Edinburgh were conducted in the premises of the two NGOs respectively, and one was carried out in the researcher's own residence. In all the interviews, the principle of confidentiality was strictly adhered to. Unlike the situation in Kerala, carers were not financially compensated for their travel.

It can be seen that the stark differences in the resources of the carers in Kerala and Scotland led to differences in the methods used to complete the interviews. For the respondents in Scotland, involvement in the study created only minor disruption of their daily lives. For the participants from Kerala, participating in the study sometimes involved taking risks of discovery that would have led to severe hardship in their lives. It is a testament to their courage and will that so many individuals from Kerala were willing to participate.

Practical Constraints

The fieldwork process in each of the settings had unique practical constraints that in turn created limitations for the research. These will be discussed separately for each context.

Kerala

The two main constraints in this context were related to travelling by the researcher and issues of confidentiality. As the carers were spread across five districts of the state, the researcher had to travel extensively for data collection. There were several instances where, upon reaching the place, the researcher would be told of the non-arrival of the carer due to reasons beyond the agency's control. The carers sometimes failed to arrive even after agreeing to participate in the study on a particular day because of a variety of practical reasons, such as a sudden deterioration in the health of their family member living with HIV/AIDS, or because they were unable to find someone to cover for their absence while they were away, or because they had financial difficulties and were unable to pay to get to the agency.

As highlighted earlier, confidentiality was a major challenge for the researcher. Throughout the fieldwork process in Kerala, the researcher had to constantly do a cost benefit analysis, where he weighed the positive benefits of developing his study and giving a voice to the carers against the potential risk of disclosure.

Scotland

In Scotland, the major constraint occurred in relation to obtaining permissions from relevant agencies and identifying carers who were willing to participate in this research. A significant amount of time and effort was spent doing this. The Glasgow-based agency, as discussed earlier, was initially considered as the focal point for contacting carers. Initial enquiries suggested that the agency was capable and willing to assist in facilitating the researcher to meet with the carers of persons with HIV/AIDS. However, this was not successful and contacts with other agencies in Glasgow also proved to be unsuccessful. Although the researcher interviewed five carers from the two cities, this was a very small sample size, and this inevitably impinged on the generalisability of the findings. Although the limitations in the sample size made some quantitative comparisons impossible, the qualitative data were valuable in providing an additional source of thematic material, and thus the data from Scotland were included in the study.

Ethical Considerations

Ethical issues are woven through all aspects of research (Ely et al., as cited in Padget, 1998). Researchers have a duty to take an ethical perspective to their research (McBurney, 1994; Minichiello et al., 1995). Given the sensitive and cross-cultural aspects (Freed-Taylor, 1994) of this study, issues of confidentiality, informed consent, trust, and reciprocity were particularly important (Babbie, 1995). Addressing these concerns also helped to ensure that the researcher adhered to the three important scientific tenets that should govern all social research: beneficence, or the maximizing of good outcomes while minimizing unnecessary risk or harm; respect, or the protection of the autonomy of respondents; and justice, or the assurance of reasonable, non-exploitative, and carefully considered procedures with fair distribution of costs and benefits (Sieber, 1992). By designing a project that had the potential of giving a voice to people who had heretofore been voiceless and pointing to ways of improving their circumstances, the researcher hoped to fulfil his ethical obligations as a researcher who cared about human concerns (Padgett, 1998).

Informed Consent

Participation in the study was entirely voluntary, and each carer was made aware that they could withdraw from the process at any point if they so wished. However, none of them opted out of the process. All the carers voluntarily signed the letter of Informed Consent.

Confidentiality

The need to take the utmost care about confidentiality is a paramount consideration in any HIV/AIDS-related research, because of the potential for serious discrimination, stigmatisation, and general distress that could occur if details of a respondent's HIV status were to be revealed to others (National Health Medical and Research Council, 2001). In all the researcher's contacts with potential and actual carers, he stressed that the information they would provide would be treated with the utmost confidentiality. Additionally, at the beginning of each interview, he reassured the carers that confidentiality and anonymity would be protected throughout the process. Irrespective of where the interview took place, he tried to ensure confidentiality and privacy. As mentioned earlier, there were instances when the interviews were conducted in the homes of the carers in Kerala. In these cases, it took greater time and effort to ensure privacy. The researcher took care to ensure that all personal details divulged were secure and that no identifiers were used on any publicly available material. To protect the anonymity of the carers, he gave each of them a pseudo-name in the study. Confidentiality was also seen as crucial when using direct quotes in writing the thesis, and names of hospitals, areas where carers lived, or any other identifying details have been carefully removed.

Trust and Reciprocity

The principles of trust and reciprocity were crucial ethical issues in this study. Reciprocity is the practice of giving in return for what one has received. As a researcher, it was important to consider giving something back to the carers. There were two aspects to this process of reciprocity that the researcher engaged in. First, the ethical issue of financially compensating some carers from Kerala arose, where carers had to spend large sums of money to attend the interviews. They were therefore given compensation equivalent to travel expenses and at times lost wages for participation in the study.

Another instance highlights the extreme poverty and misery faced by some of the carers who graciously agreed to participate in the study. One of the carer's husbands was dying of AIDS—she and her family were literally chased out of their village when her husband's AIDS status was discovered. The family became destitute and as a result the local police came and "threw" her husband into a charitable home run by missionaries for destitute people who are not accepted anywhere else. The missionaries told the researcher that often the police forced them to accept people dying with AIDS. She and her child were stranded, because there was no other support in place. She subsequently sought refuge with her sister, (who herself was very poor) and visited her husband in the hospice. The day the researcher met her and she agreed to be interviewed, her husband was critically ill. During the interview she broke down and told the researcher that she had been able to travel only because of the magnanimity of the doctor, who paid for her to travel with her child. She said that they had not eaten for two days, which seemed apparent in their gaunt and dazed faces. The researcher was extremely moved by the wretchedness of her situation. At the same time he was struck by the sheer resilience and commitment that this woman exhibited in the face of such extreme adversity, and the only way in which he could reach out to her was to give her all the money that he had with him (Rupees 1100--approximately £15.00 which is fairly large sum of money in Indian terms).

A second issue involved trust. The element of trust between the carers and the researcher was crucial in encouraging the respondents to speak frankly and allow the researcher to gather honest, reliable accounts (Lofland & Lofland, 1995). The researcher thus had an obligation to reciprocate, by sharing details about his own life when participants questioned him about himself. He answered their questions as briefly and honestly as possible, without shifting the focus from the carers to himself. The researcher also endeavoured to be reciprocal by being open and accepting in all interactions with his carers, and by being an empathetic listener.

Researching Sensitive Subjects

Sensitive subjects are those that present some element of risk or seem threatening to the participants (Renzetti & Lee, 1993). Such subjects often address some of society's pressing issues (Sieber & Stanley, 1988), and they may include areas that are private or stressful, or potentially expose stigmatising or incriminating information (Lee, 1993). Researching the lives of carers' of HIV-positive people definitely involves a sensitive subject, and the research involves considerable risk to participants who are already vulnerable. The study of areas related to HIV/AIDS is also a highly emotive subject, with emotional implications for both the respondent and the researcher (Bourne, 1998).

This research obliged the researcher to build an ethical relationship based on respect, trust and "cultural sensitivity." His knowledge, skills, and values enabled him to gain access to the carers, to learn about their way of life, and to communicate in ways that they regarded as significant (Sieber, 1992). By ensuring confidentiality and asking questions about painful experiences with sensitivity (Padgett, 1998) the researcher endeavoured to build a relationship in which minimum distress was caused to the carers during the interview process. Equally crucial was the fact that the researcher was a man interviewing mostly women. It was essential to understand, recognise, and exercise cultural sensitivities whilst conducting research involving members of the opposite sex, particularly in the Indian context, where traditionally this type of interaction has been restricted.

Data Analysis

The aim of the data analysis was to explore the experiences of carers who cared for their family member living with HIV/AIDS, such that their experiences were portrayed as accurately as possible, to preserve the richness and uniqueness of the data. As the research combines both qualitative and quantitative methods, the analysis involved handling the data that emerged from these methods separately.

Qualitative Analysis

Qualitative research methods are primarily concerned with in-depth study of human phenomena in order to understand their nature and the meaning that they have for the individual involved (Hunt, 1991). As discussed earlier, data were analysed using some elements of the grounded theory. The process of data analysis undertaken is described as a linear process; however, it must be understood that the stages overlapped and were not linear. In passing, it might be noted that considerable thought was given to the use of a software package for qualitative data analysis, such as NUD*IST (Qualitative Solutions and Research, 1997). However, it was felt that the process of inputting the data and becoming proficient with the programme itself did not necessarily equate with the time it would take to master the package. Hence in this study, no software package was used for analysing the qualitative data.

Transcription and Translation of Interviews

The analysis of data began with the transcription of interviews. The initial process of transcribing the interviews in Kerala began as each interview was completed. However, at this stage it did not involve a full transcription. It involved listening to the tapes and jotting down important categories and themes that were emerging from the interviews. A complete transcription was not possible at the time due to a number of practical constraints. The researcher was travelling extensively and had limited time in the evenings to work on transcriptions; he also did not have access to a computer, thus full transcriptions would have been too laborious; and finally, the researcher often spent evening planning and preparing for the next day's interviews.

During the process of this initial transcription in Kerala, the researcher began the process of "mental mapping" of concepts that were emerging from the data, by following a simple inductive process to organise the various categories that emerged from the data. The initial task was to find the concepts that helped the researcher to make sense of what was going on in the scenes documented by the data, which led to the process of conceptualisation (Hammersley & Atkinson, 1995), which, in turn, enabled him to discover what the experiences of the carers were.

As the researcher went ahead with this process, he discovered that certain concepts were repeating themselves in the data. It thus became evident that the data collection and mental mapping had reached a stage of saturation (Glaser & Strauss, 1967). This reflects the value of conceptualising and transcribing simultaneously, in order to reach data saturation.

Having completed the fieldwork in Kerala, the researcher began the process of transcribing the full interviews. The researcher listened extensively to the recordings and started transcribing what was being said in Malayalam, which is the mother tongue of the carers and of the researcher. Although the researcher's writing skills in Malayalam are satisfactory, the process of writing each word that was being said was becoming torturous. He then started transcribing all the interviews in the Roman alphabet, which expedited the process greatly. Initially the researcher did a literal translation, but on re-reading the translations, there was a sense of disjointedness. The researcher therefore started translating the interviews in his own words, trying to keep as close to the essence of what was being said, without losing the cultural flavour of the words used.

The interviews in Scotland were transcribed directly into English. It should be noted, however, that there was little possibility of saturating the data, due to the limited size of the sample available in Scotland. This was discussed with the investigator's research supervisors, who accepted the limitations of this situation.

The Development of Categories and Themes

Data analysis in qualitative research involves the development of categories and themes. Thus, after completing a rather lengthy process of transcription and translation, the transcripts were subjected to a close reading in order to develop the categories. The broad categories that were identified in the process of data saturation (done in the field, while in Kerala) from the Kerala sample, along with the categories that emerged from the Scottish sample, were examined for their relevance and importance, with the objective of reducing the complexity of the data to a small number of categories. The researcher used elements of open coding (Glaser &

Strauss, 1967), that is, examination of the transcripts line by line, sentence by sentence, and paragraph by paragraph in order to allow the data to reveal as many categories as possible.

By exploring the different categories, a refinement of categories was made. The goal was to uncover as many distinct themes as could be found in the data. While developing the categories into themes, categories that were found to have similarities were put together to constitute a theme. Conversely, categories that were atypical or unique also led to the development of themes. The themes form the basis of the description and explanation of the experiences of family carers of persons with HIV/AIDS, discussed in Chapter 6. The researcher then developed a synthesis of the themes, centred around the three unifying concepts of struggle, commitment, and resilience, which will be discussed further in Chapter 8.

It should be noted that, for the purpose of analysis, the sample from Kerala and Scotland was treated as two units, as this enabled the researcher to develop better insight into the experiences of caring in each context. Moreover, the researcher was careful at all times to adhere to the principle of theoretical sensitivity, that is, having an insight into the data coupled with the ability to give meaning to the data, along with the capacity to understand and the capability to separate data that is pertinent from that which is not (Strauss & Corbin, 1990). The researcher's prolonged engagement with carers in the field, together with his own reading of the literature enhanced his sensitivity.

Quantitative Analyses

Following the completion of WOC and SRQ, the responses were coded for analysis. All quantitative analyses were completed using the Statistical Package for the Social Sciences (SPSS Version 10.0.5, 1999).

Demographic and Setting Data

For the demographic and setting data, the frequency and percent of respondents giving each response were computed separately for the Kerala and Scotland samples.

Median scores and ranges were computed for the Kerala and Scotland samples on each of the nine scales of the Ways of Coping (WOC) measure and for the total score earned on the Self Reporting Questionnaire (SRQ). The scores of the Kerala and Scotland samples on the nine WOC scales and on the total for the SRQ were compared using Mann-Whitney U Test. Details of these analyses are presented in Chapter 7.

The relationships among the variables were also explored. Pearson correlation coefficients were computed among the scores on the nine WOC scales, the SRQ total scores, and selected demographic and setting variables. Multiple regression analyses were also completed for selected variables, as described in Chapter 7. For all quantitative analyses, the probability level for statistical significance was set at .05.

Comparison of Ways of Coping Scores

To determine whether individuals in the two settings used different coping strategies, the Ways of Coping scores for the Kerala and Scotland samples were compared using the Mann-Whitney U Test. This test was chosen because of the small size of the Scotland sample, which did not allow the assumptions necessary for a parametric test such as the t-test to be met.

Exploratory Regression Analyses

Multiple regression analysis was used in order to explore the relationships among the quantitative variables used in this study. Details of these analyses will be given in Chapter 7. It should be stressed that these analyses are exploratory, due to the small size of the Scottish sample and great caution should be applied when drawing conclusions from the findings or making generalisations because the small size of the sample involved in this study may influence the reliability of the results.

Conclusion

This chapter has described the process of developing the research methodology for this study—a methodology that would both be broad in scope as well as rigorous so as to ensure the findings and conclusions are trustworthy, useful and valid. The researcher aimed to develop a qualitative study that would reflect the experience of the family carers' day to day lives, as they care for a family member living with HIV/AIDS. A secondary goal was to explore quantitatively the effect of caring for a family member living with HIV/AIDS on the carer's ways of coping and mental health. To achieve these ends, 23 family carers in Kerala and 5 carers in Scotland were selected, partly on the basis of purposive sampling (Kerala) and partly on the basis of availability (Scotland).

Each of the carers completed an in-depth, open-ended interview, which was based on an interview guide designed for this study. The interview explored the experience of caring for a family member with HIV/AIDS from the perspective of the carers. The participants also completed the WOC (Folkman & Lazarus, 1985) as a measure of coping strategies and the SRQ (World Health Organisation, 1994) as a measure of mental health problems. The interview transcripts were subjected to qualitative analysis, using elements of the grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990), in order to develop a set of themes that captured the meaning of the experience of the carers. The WOC and the SRQ data were analysed in relation to demographic variables and compared across the two settings, Kerala and Scotland. Further quantitative analyses were also done, on an exploratory basis.

The next chapter presents a profile of the family carers in the two contexts in which the study was based. This provides a deeper understanding of the lives of the carers and their family member living with HIV/AIDS. The chapter helps to facilitate a foundation through which the life experiences, coping, and mental health of family carers of persons with HIV/AIDS is studied, and serves as a background for the substantive material to be presented in later chapters.

CHAPTER 5: PROFILE OF THE CARERS AND THEIR FAMILY MEMBER WITH HIV/AIDS

Introduction

The previous chapter detailed the research methodology utilised in the study and provided an understanding of the research questions and research design. This chapter presents a socio-demographic profile of the carers and of the family members living with HIV/AIDS in Kerala and Scotland.

The profile offers an insight into the baseline conditions faced by those who are both affected and infected by HIV/AIDS. This general picture of the varied conditions faced by these respondents will serve as a background for the more personal concerns that are described in the succeeding chapters. The demographic and background data will also serve as indicators of the extent to which the sample included in this study is representative of the larger population of families affected by HIV/AIDS and will also suggest important ways in which the Kerala and Scotland samples differed from one another.

As noted in Chapter four, the sample size included 23 respondents from Kerala and 5 respondents from Scotland, who came from varied backgrounds. However, only selected demographic aspects of the population have been highlighted using tables and the others are discussed in the text, in order to minimise the monotony of tables.

Age, Gender, and Marital Status

Table 2 presents the age distribution of the respondents in Kerala and Scotland. It can be seen from the table that a majority of the respondents in Kerala were under the age of 40, with the largest group (43.5%) falling in the age range of 31 to 40 years and the second largest group (34.8%) falling between the ages of 21 and 30 years. In contrast, the group from Scotland, though considerably smaller, was more spread across the age range from 31 to 60 years of age.

Table 2

Age Distribution of the Carers (Respondents)

Age Range	Frequency	Percent
	Kerala	
21-30	8	34.8
31-40	10	43.5
41-50	4	17.4
51-60	1	4.3
Total	23	100.0
	Scotland	
31-40	2	40.0
41-50	2	40.0
51-60	1	20.0
Total	5	100.0

These data suggest that the burden of caring for family members with HIV/AIDS often comes during the years when the carers would be expected to be at their most productive. For the Kerala sample, who were mainly in their 20's and 30's, these years would also be a time when the carers are raising children, and thus the carers may be faced with multiple and often conflicting demands for their time and energy. It is harder to discern any trends in the smaller Scotland sample.

In terms of gender, the majority of the respondents in both Kerala and Scotland were female, accounting for some 74 percent of the Kerala sample and 80 percent of the Scotland sample. These data would be consistent with the traditional role of women in providing care for family members, particularly those who are sick or injured.

Historically women, in their roles as mothers and as wives, have often assumed the duties of caring for family members when they became ill.

The two groups differed considerably in marital status. The majority (96%) of the Kerala sample was married, while only one of the Scotland respondents described herself as married. One of the respondents from Scotland was single, and the rest described themselves as married, divorced, separated, or widowed. These data reflect differences in the identity of the family member with HIV/AIDS. In the majority of cases in the Kerala sample, the carers were the wives of the HIV/AIDS-affected husband. This was not the case in the much smaller Scotland sample, where the carers were often parents of the family member with HIV/AIDS.

Education, Occupation, Residence, and Family Composition

Table 3 presents the educational background of the respondents. The data for education are presented as the number of years of education completed. This method was chosen because of differences in the ways that levels of education were defined in Kerala and Scotland. In particular, the definitions for secondary and higher secondary education differed between the two communities. Rather than using the terms *primary, secondary,* etc., the number of years of schooling for each level are indicated.

The majority of the Kerala respondents had eight to ten years of education, but a significant number (21.7%) reported seven or fewer years of education. Roughly one fourth of the Kerala respondents reported education beyond ten years. In contrast, 80 percent of the Scotland sample reported having 12 or more years of education, and none of the respondents had less than eight years of education.

Table 3

Educational Background of the Respondents

Years of Education	Frequency	Percent
	Kerala	
Up to 7	5	21.7
8 to 10	11	47.8
11-12	6	26.1
Degree	1	4.3
Total	23	100.0
	Scotland	
Up to 7	0	0
8-11	1	20.0
12-13	2	20.0
Degree	2	40.0
Total	5	100.0

The two groups also differed in occupation. Table 4 presents a breakdown of the occupations of the respondents. The majority (73.9 %) of the Kerala sample could be classed as "housewives" who had no means of earning money outside the home. The few remaining respondents were working in a variety of small scale, self–employed occupations, including farming and skilled trades, where the income generated was at the level of subsistence. The majority of the Scotland sample reported working in administrative positions, with a substantial minority of homemakers as well. These data suggest that the two samples were different in terms of education and employment as well as income, which has relevance for the ability of the family members to cope with the burdens of providing care for the family member with HIV/AIDS.

Table 4

Occupation of the Carers

Occupation	Frequency	Percent
	Kerala	
Housewife	17	73.9
Small shop owner	1	4.3
Farmer	2	8.7
Goldsmith	1	4.3
Travel agent	1	4.3
Tailor	1	4.3
Total	23	100.0
	Scotland	
Administrative assistant	3	60.0
Home Maker	2	40.0
Total	5	100.0

The carers in the Kerala sample reported living in small towns and villages, while all of the carers in the Scotland sample came from cities. An understanding of where the carers lived is important because, HIV/AIDS related services are more often located in urban areas. In the context of Kerala, the carers reported great difficulties in accessing the available services as they lived away from the city.

As Table 5 shows, the majority of Kerala respondents were living as husband and wife, with or without children. A substantial number of households also included parents or siblings of one of the spouses. In the Scotland sample, a majority of the respondents reported living with their parents and children. For the purposes of this study, it was important to develop an understanding of the family composition, since it would throw light on the level of family support that might be available to the carers.

Table 5

Family Composition of the Carers

Family Composition	Frequency	Percent
Kerala		
Husband & wife	2	8.7
Husband, wife, & children	12	52.2
Husband, wife, children,& parents	3	13.0
Husband, wife, siblings,& parents	6	26.1
Total	23	100.0
Scotland		
Husband & wife	1	20.0
Partners	1	20.0
Parents and children	3	60.0
Total	5	100.0

Table 6 presents the relationship of the carer to the family member with HIV/AIDS. Most of the carers in the Kerala sample were the wives of the member with HIV/AIDS, although a few parents and siblings served as carers. In the Scotland sample, the majority of the carers were parents of the individual with HIV/AIDS. It should be noted that "partner" in the context of Scotland refers to a partner of the same sex. Again, these data suggest that the Kerala sample and the Scotland sample differed considerably in terms of the context in which caring took place. In Kerala, caring took place primarily in the context of a marital relationship. In the Scotland sample, the numbers were too small to show a clear pattern, but it appeared that the parent-child context was more predominant.

These data reflect important differences in the quality of the relationship between the carer and the HIV/AIDS-affected person in the two settings. Caring for a spouse with HIV/AIDS may be affected by a much greater level of emotional intensity, because of the intimacy of the marital relationship. Also, the potential for infection of the carer with HIV is much greater, due to the sexual nature of the relationship. Thus the Kerala and Scotland samples differed greatly in the emotional nature of the relationship between the carer and the HIV/AIDS-affected person.

Table 6

Relationship of the carer to the family member with HIV/AIDS

Relationship	Frequency	Percent
Kerala		
Wife	17	73.9
Mother/parent	2	8.7
Sibling	4	17.4
Total	23	100.0
Scotland		
Wife	1	20.0
Partner	1	20.0
Mother/parent	3	60.0
Total	5	100.0

Characteristics of the Family Member with HIV/AIDS

It was important to have an understanding of the characteristics of the family member living with HIV/AIDS who were being cared for by the respondents in the study. This provided a glimpse of the variety of concerns that the carers were facing as they cared for the HIV/AIDS-affected family member.

Table 7 presents the data on the age of the family member with HIV/AIDS in each sample. In nearly all the cases, the individual with HIV/AIDS was under 40 years of age. In the Kerala sample, over 80 percent were between the ages of 31 and 40, with two individuals under age 30 and two individuals between 41 and 50. In the Scotland sample, the majority (60%) were age 21 to 30 and the rest were between the ages of 31 and 40.

Table 7

Age of the family member with HIV/AIDS

Age Range	Frequency	Percent
	Kerala	
21-30	2	8.7
31-40	19	82.6
41-50	2	8.7
Total	23	100.0
	Scotland	
21-30	3	60.0
31-40	2	40.0
Total	5	100.0

These data seem to reflect the worldwide statistics regarding HIV infection. HIV/AIDS often strikes individuals during their most productive years, when they could be expected to work, to care for offspring, and to contribute to family resources. Families living with HIV/AIDS not only have the burden of providing care to a sick member, they also lose the contributions that the person with HIV/AIDS might have been able to make if they were well.

In both Kerala and Scotland, the majority of the individuals with HIV/AIDS were males. Over 90 percent of the Kerala sample were male, and 80 percent of the Scotland sample were male. The two groups differed as to marital status of the individual with HIV/AIDS. The majority (83%) of the individuals in the Kerala sample were married, while the majority (60%) of the Scotland sample were single. As mentioned earlier, these differences seem to reflect important differences in the family context of caring for HIV/AIDS in the two settings.

Table 8 presents the educational attainment of the family member with HIV/AIDS in each setting. As with the carers, the educational attainment is higher in the group from Scotland, although the differences are not as great as they were in the case of the carers. The majority (approximately 83%) of the sample from Kerala reported attaining eight or more years of education, while the remainder (17.4%) had seven or fewer years. In contrast, all of the individuals from Scotland had eight or more years of education.

Table 8

Education of the family member with HIV/AIDS

Years of Education	Frequency	Percent
	Kerala	
Up to 7	4	17.4
8 to 10	14	60.9
11-12	4	17.4
Degree	1	4.3
Total	23	100.0
	Scotland	
Up to 7	0	0
8-11	2	40.0
12-13	2	40.0
Degree	1	20.0
Total	5	100.0

The data for occupation of the family member with HIV/AIDS are presented in Table 9. Most of the individuals in the Kerala sample were engaged in relatively unskilled trades, such as truck driving and manual labour. A substantial number (21.7%) were described as Gulf Returnees. In contrast, the majority of the individuals in the Scotland sample had administrative or professional positions. As with the case of the occupation of the carers, the differences in occupation of the family member with HIV/AIDS between the Kerala and Scotland samples suggests the differences in economic resources available to the carers in the two settings.

Table 9

Occupation of the family member with HIV/AIDS

Occupation	Frequency	Percent
	Kerala	
Driver	10	43.5
Gulf returnee	5	21.7
Manual labourer	3	13.0
Housewife	2	8.7
Small shop owner	3	13.0
Total	23	100.0
	Scotland	
Administrative assistant	3	60.0
Musician-DJ	1	20.0
IT professional	1	20.0
Total	5	100.0

Health of the Family Member with HIV/AIDS

All of the carers in the current study were dealing with symptoms of active HIV or AIDS in the affected family members. As Table 10 shows, slightly more than half the respondents in each setting were dealing with symptoms of AIDS in the affected family member. In the remaining cases, the family member was symptomatic for HIV, but had not yet developed the full AIDS syndrome. In all cases, the affected family member had been in good health prior to HIV infection.

Table 10

Health of the family member with HIV/AIDS

Health condition	Frequency	Percent
	Kerala	
Symptomatic for HIV	11	47.8
Symptomatic for AIDS	12	52.2
Total	23	100.0
	Scotland	
Symptomatic for HIV	2	40.0
Symptomatic for AIDS	3	60.0
Total	5	100.0

These data reflect the fact that the need for caring by family members generally comes relatively late in the progression of HIV/AIDS. All of the participants in the study were dealing with significant health impairment of the affected family member, which was likely to consume considerable time and energy. The burdens experienced by the participants in the study were thus considerable and, in many cases, growing.

One indicator of the functioning of the affected family member is the ability to continue working. In nearly all the families studied, the affected family member was no longer able to work. This was true for over 90 percent of the affected family members in the Kerala sample and for all of the affected family members in the Scotland sample. Thus loss of the income provided by the affected family member was also an issue, and it served as an added source of stress for the family carers.

Access to Medication and Services

Table 11 shows the medication status for the family members with HIV/AIDS in Kerala and Scotland. The majority (65.2%) of respondents in Kerala reported that the affected family member was using some sort of medication, but a substantial number (34.8%) had no medication at all. In contrast, all of the respondents in Scotland reported that the affected family member received medication. These data again reflect the differences in resources available to the family carers in the two settings.

Table 11

Medication of the family member with HIV/AIDS

On medication	Frequency	Percent
	Kerala	
Yes	15	65.2
No	8	34.8
Total	23	100.0
	Scotland	
Yes	5	100.0
No	0	0
Total	5	100.0

The two settings also differed greatly as to the type of medication used by the affected family member. As Table 12 shows, none of the affected members in Kerala were receiving combination therapy, while all of the affected family members in Scotland had this treatment. Instead, the family members with HIV/AIDS in the Kerala sample relied on symptomatic treatment, Ayurvedic medicine, or homeopathic treatment.

For carers and the positive persons in Kerala, combination therapy was out of their reach and many were not even aware of this. It was observed that state hospitals and other publicly funded projects were involved mostly in awareness building and condom distribution. As can be seen from the table, only a small number (17.4%) of the participants could afford allopathic treatment for symptomatic HIV/AIDS. The private clinics that provided this service charged exorbitantly and most of these clinics were based in towns away from the villages. This led both carers and the family member with HIV/AIDS to seek alternative treatment in several instances.

Table 12

Type of medication taken by the family member with HIV/AIDS

Type of medication	Frequency	Percent
Kerala		
Allopathic, symptomatic treatment	3	13.0
Ayurvedic medicine	9	39.1
Homeopathic medicine	3	13.0
No medication	8	34.8
Total	23	100.0
Scotland		
Combination therapy	5	100.0
Total	5	100.0

Kerala has been credited with making advancement in alternative medicine, which has also made inroads into HIV/AIDS treatment. Though no scientific data were available to verify the effectiveness of this treatment for HIV/AIDS, both carers and practitioners reported that the treatment had brought about noticeable improvement in the health status of the positive persons. During the course of data collection, it emerged from personal communication between the Medical Director (of one of the treatment centres) and the researcher that scientific experiments were being conducted to verify the effectiveness of this treatment in collaboration with the Johns Hopkins University Medical School in Baltimore (United States).

The two settings also differed in regard to the availability of supportive counselling services for the carer or the family member living with HIV/AIDS. Fewer than one fourth (about 22%) of the respondents in Kerala reported having any access to these services, while all of the respondents in Scotland reported access to counselling for himself or herself or the affected family member. Thus it appears that the Kerala participants were dealing with isolation in addition to the other issues associated with caring for a family member with HIV/AIDS. Because of the stigma associated with HIV infection, this isolation was also acute. This issue will be explored further in later chapters.

Conclusion

This chapter presented a profile of the carers on whom this study was based and a glimpse of the family members whom they cared for. The statistical realities of the HIV epidemic are apparent in the contrasts between Kerala and Scotland. The differences between the respondents in the two communities are quite marked, particularly in regard to education, economic resources, and medical resources. The carers in Kerala are coping not only with the burdens imposed by HIV/AIDS, but also with the additional burdens of poverty and lack of access to proven medical treatment. These fundamental differences are likely to be important influences on the more personal experiences of the carers, as will be seen in the next chapters. By developing an understanding of these realities for the carers as well as the family member who was infected with HIV/AIDS, this chapter provides a background for understanding the experiences, coping, and mental health of family carers of persons with HIV/AIDS.

The next chapter discusses the qualitative findings of the study. It describes the wide-ranging effects that caring for a family member with HIV/AIDS can have upon the carer. It also illustrates these effects with case vignettes from both the settings. These case vignettes provide a more individualized and deeper insight into the experiences of caring for a family member with HIV/AIDS.

CHAPTER 6: QUALITATIVE FINDINGS: EXPERIENCES OF THE CARERS

Introduction

The previous chapter has provided demographic and background information of the carers in this study, which serves as a backdrop for the qualitative findings. This chapter will present the qualitative findings in detail. The goal of this chapter is to present the themes and sub-themes that were derived via qualitative analysis of the data, and to illustrate these themes with examples taken from the carers' accounts.

This chapter is divided into four sections. The first section gives a brief introduction to the chapter. The next section presents the six themes in detail and illustrates how they were experienced in each of the two research contexts, Kerala and Scotland, followed by the third section that presents case vignettes that illustrate these themes. Two vignettes were chosen to illustrate the circumstances of the carers in Kerala, and one vignette was chosen to illustrate the circumstances in Scotland. The chapter concludes with some observations.

This chapter describes the enormous impact that HIV/AIDS has on the lives of the family carers of HIV-positive persons. It looks at the challenges that they face in caring for their loved one with an unpredictable illness, with little or no training, guidance, or support. It explores the multifaceted psychosocial issues involved in caring and coping for a family member living with HIV/AIDS, such as the stigma of HIV/AIDS and the economic consequences of diagnosis. Some families in both contexts experienced rejection from their relatives and friends, loss of jobs, ostracism, and harassment, which were similar to conditions described by Bor et al. (1993). The apprehension that disclosure would lead to recrimination from society prevented many of the carers from seeking social support, and this experience was also similar to other reports in the literature (Hays et al., 1990; Smith & Rapkin, 1995). Finally, the changeable nature of the illness trajectory created its own hardships. As noted by Rapkin et al., (2000), the course of HIV is often very unpredictable, making it impossible for the carers to anticipate what problems they will face and when. These qualities of the caring experience are made even more difficult when caring occurs in a context of poverty, unemployment, poor health care, nonexistent financial support, and widespread ignorance.

Themes Emerging from the Data

After completion of the analytic process described in the methodology chapter (Chapter 4), six distinct themes emerged. These themes were the product of a process of refinement, in which a large number of categories, each of which described a unique aspect of the participants' accounts, were organized into a smaller number of themes. These themes were chosen with the goal of encompassing the breadth of the experiences described by the carers, while still reducing the volume of data to a reasonable level and allowing the patterns of consistencies, as well as important instances of uniqueness, to emerge.

Each theme will be presented with illustrations of the underlying material that contributed to the development of the theme. The themes are presented in a more or less chronological order, according to their place in the carers' accounts of their experiences. This order allows for a natural progression of the themes that reflects the experience of the carers as they encountered various aspects of the process of dealing with the HIV/AIDS diagnosis and all that it entailed for their lives.

Arranging the themes in this order allowed the researcher to piece together the different themes like the *bricoleur* (Denzin & Lincoln, 1994; Levi-Strauss, 1966) using the theme that followed a course of natural progression. This enabled the researcher to form a *bricolage* of categories that facilitated an understanding and interpretation of the phenomenon under analysis (Denzin & Lincoln, 1994). The goal is to allow a complete picture of the carers' situation to emerge, theme by theme. Becker (1978) likens the process to the image of a mosaic in which each theme, as it is added, enhances the understanding of the total picture.

Reflecting the experiences of the carers, the study begins with the advent of HIV/AIDS in the lives of the carers. This theme includes sub-themes that reflect the circumstances of discovery, reactions to the discovery, prior awareness of HIV/AIDS, and the process of becoming a carer. This theme is followed by a theme reflecting the physical, emotional, social, and economic experiences encountered in the process of providing care. The next theme focuses on issues of family dynamics and parenting that arose in the caring process. The issue of being a carer and also being HIV-positive is discussed next. The final two themes discuss issues of support: first, the issue of informal support, and then that of formal support.

The Advent of HIV/AIDS in a Family Member

One set of experiences that were consistently described by the carers concerns the circumstances of discovering that a family member had HIV/AIDS and the process of undertaking the role of family carer. The researcher began by asking the carers about how they came to know that their family member had been diagnosed with HIV or AIDS. This seemed like a logical place to begin the interview, and set the stage for a rapport in the interview. Beginning the interview using these questions at this stage, gave the carers a point to focus on in order to begin their narrations of their experiences.

The point of discovery also seemed to have significance for the carers. It was the beginning point of their story of living/caring for their family member living with HIV/AIDS, and starting with this experience helped the respondents to go "back to the beginning". Many of the carers also seemed to find it helpful to talk about this aspect of their experience. Like others who have experienced a traumatic event, they seemed to have some need to talk about it and to tell their story as a coherent tale, starting at the beginning. Cohler (1994) speaks about persons in a therapeutic interview/environment. According to him, sharing one's experiences is particularly significant to the respondent. He suggests that respondents' experiences usually flow rather freely, much as a narrative, with a beginning, middle, and an alluded end.

Further, according to Sherman and Reid (1994) the predominant form in our culture is a story that has a plot—a beginning, middle, and end. Reissman (1994) suggests that the researcher is taken into the narrator's past, where the respondent recapitulates what happened then to make a point. She points out that respondents construct their stories as dramas in three parts, beginning with a *prehistory*, the *incident*, and ending with the *aftermath*.

The overall experience of the advent of HIV/AIDS in the lives of the carers includes a number of facets, which are reflected as sub-themes. These include the varying ways in which the carers discovered that their loved one was HIV-positive, and their reactions upon learning the news. They also reflect the background knowledge about HIV/AIDS that the carers brought to the situation. Finally the decision to undertake the process of providing care is discussed. These facets, together, depict the experiences of the carers as they experienced a dramatic change in their lives—the advent of HIV/AIDS.

Circumstances of Discovery

Any circumstance in life that cuts to the heart of our being touches us most profoundly. We tend to remember how the change first touched our lives, and to see this circumstance as a dramatic turning point. The discovery of HIV/AIDS in a family member is such a circumstance. This section explores the ways in which carers found out that their family member was suffering from a grave illness such as HIV/AIDS, and relates the beginnings of their lives as carers.

For nearly all of the respondents, their discovery that a family member was infected with HIV took place when that person began experiencing deteriorating health. This was the case for 22 out of the 23 respondents in Kerala and four out of the five respondents in Scotland. Since it may take several years after infection before the infected person begins showing significant symptoms, this finding suggests that in most cases, the family member had been infected for some time before the carer became aware of it.

Fourteen of the respondents in Kerala became aware that a family member was infected with HIV when that person developed health problems that are characteristic of HIV infection. Respondents spoke about typical HIV/AIDS-defining symptoms such as diarrhoea, fever, severe cough, weight loss, and renal problems. Some examples illustrate the nature of this experience.

Meena discovered that her husband had AIDS when husband was taken to the hospital with diarrhoea, fever and a severe cough. She said, *"...the doctors did a blood test ... they told me that he was suffering from a very serious illness called AIDS."*

Bindu had a similar experience when she took her husband to the hospital with symptoms of renal failure. She said:

> *He was unable to go to the toilet and his legs were very swollen ... he had become very weak and had lost a lot of weight too ... when the doctor did some tests, he told his brother and me that my husband was too sick, he did not have long to live, because he had AIDS.*

A few others (4, n= 23) were tested due to other health problems that were not necessarily indicative of HIV/AIDS.

Sheela discovered from the hospital, when her husband was admitted in a multi-speciality hospital for kidney stone operation. She spoke of her horror when the doctor told her that he had arranged for a routine HIV blood test before the operation, and that it had come back positive.

Kanaran's son was involved in a road accident from which he was not recovering. He spoke about the anxiety that his family were experiencing. He said:

> *Because he was already in the hospital, the doctors decided to do further investigations to see why he was not responding to the medicines, that is when they did a HIV blood test, and that is how we found out that he had HIV.*

One respondent in Kerala (Sheena, discussed in the first case vignette in Section C, later in this chapter) discovered the HIV infection in her husband during the process of blood donation. Sheena was full term pregnant and was admitted into a private hospital in a large town. Towards the time of delivery, the doctor confirmed that she would need a caesarean and asked them to arrange for blood in case she required a blood transfusion. As is customary when a blood transfusion is anticipated, family members were tested as potential donors, since a community blood bank is not generally available. When her husband was tested as a potential donor, his HIV infection was discovered.

Finally, five carers learned that the affected family member was infected with HIV upon that person's return from abroad. These carers had husbands who had travelled to work in the oil-fields of the Middle East and returned with HIV infection. As discussed in Chapter 3, these young men had travelled to the Middle East with the hope of finding well-paid work and a better life. Because they live away from their homes and partners, workers in this circumstance are more likely to engage in paid or unpaid casual sex, often with a sex worker and without protection, thus rendering themselves particularly vulnerable to HIV and AIDS.

Thusha's husband was working as a welder in a factory. He had been complaining of frequent illnesses over the past year. As the frequency of the illnesses became more regular, he took leave to go home and recuperate. When he visited the doctor in a nearby hospital, the first test that the doctor made him undertake was the HIV test. She said:

> *He looked very thin and as if he had not eaten for too many days. His eyes had a sick look, so the doctor made him tell where he had been and when he heard that he had been in Bombay for many months looking for a job, before he went to the Gulf, he thought he needed to take the test and that's how we found out that he had HIV.*

Leelavathi's experience was very similar to Thusha's, except that her husband was tested in the Gulf by his employers and subsequently relieved of his job when they discovered his HIV status. She said:

> *When he first told us that he was coming in 2 days time, I was very excited at the thought of meeting him again. How was I to imagine that he would be bringing this heartbreaking news with him?*

One carer (Sabira) and her husband discovered that he was HIV positive when he took a mandatory HIV/AIDS test, to enable him to take up a new job in the Gulf. She spoke of her complete shock and disbelief at discovering that he was positive. She said:

> *He was a healthy man and had worked in the Gulf for three years. He was looking forward to this new three-year contract ... We were making so many plans of building our own home with the money he earned when he came back .... Instead we got this shock; he would never be able to go to the Gulf again. They do not allow you the minute you have HIV, even if you are well and have no problem they just do not allow you. Not only do we have this horrible news, but we have lost all the money we paid to the agent for his job which we could have used for his treatment.*

The majority of the respondents in Scotland (4, n=5) also learned about the infection when the family member developed health problems.

Kate, Julia and Trisha all spoke of their anxiety and distress at the deteriorating health of their children. Trisha said that she had a niggling feeling that her daughter's ill health was something more serious than a common cough and cold. She said, *"I had this strange feeling, deep in here* [pointing to her heart] *that something was not quite right ... my feelings were confirmed when the doctor told us that she had tested positive for HIV".*

Kate's son was working in a large city in the UK in the entertainment industry. He had been unwell for a while. The time when they discovered that he was HIV positive, he had returned to Scotland because he was unable to go on working. A HIV test brought to light his diagnosis, something that was totally unexpected. She said, *"He had been very unwell, but never in a million years did I fear HIV for my lad ... it was a bolt out of the blue, a complete bolt out of the blue".*

Ann's husband too had been rather unwell. Her husband had a chest infection following which his health rapidly deteriorated. Tests revealed that he had advanced HIV. Subsequently it was discovered that she too was HIV positive. She said:

> *Well, I first found out, when my husband had been unwell for a long time. He was investigated for all sorts of things, and the only thing they could then think of, and the only thing that was left was HIV and he tested positive.*

Archie said that he discovered his partner's status when his partner disclosed it to him. Archie recalled that he and his partner were having a drink when suddenly, his partner suggested that he had something serious to discuss with him. He said, *"I had been to see the doctor ... I have tested positive"*.

It can be seen from the varied responses that the carers discovered their family member's HIV status in a number of ways, the most significant one being deteriorating health. These carers were dealing with a mystery—the unexplained ill health of a loved one. Once the HIV was discovered, carers had to come to terms with the diagnosis in one way or the other. The next section discusses their emotional responses to the discovery.

Emotional Responses to the Discovery

As might be expected, learning about the HIV infection of a loved one was a very emotional experience for the carers in the study. Since HIV/AIDS is generally understood as a fatal condition, a confirmed diagnosis can be a substantial shock for the HIV/AIDS-affected person and other family members. Once an HIV/AIDS diagnosis has been made, both the person diagnosed and their loved ones/carers are likely to experience the stages delineated by Kubler-Ross (1969) that include denial, shock and anger, bargaining, resignation, and acceptance.

Carers in both settings reported a range of emotional reactions, many of which expressed the level of pain and distress they experienced. A large majority in both contexts (22, n=23 in Kerala, 4, n=5 in Scotland) reported some sense of shock or panic as an initial reaction. The panic and the shock experienced by carers seemed to manifest itself physically. This was particularly true for the female carers, who were the mothers or wives of the HIV-positive person.

Maya, from Kerala, spoke about the shock and complete panic that she experienced when the doctor told them that her husband was very unwell, with a terrible, infectious disease. She recalled her reaction: *"I felt as though the ground under my* *feet was slipping away and as though I would fall ... I was so shocked that my body would not stop shaking".*

Julia, from Scotland, spoke about the fear that gripped her when she heard about her son's HIV diagnosis. She said: *"For a moment there I felt as though no words would come out of my mouth, I was just so shocked ... but when the panic started creeping in, I felt this terrible fear stabbing through my stomach".*

Very few of the carers in either Kerala or Scotland were male, so it is difficult to get a clear picture of their reactions. One male carer from Kerala (Ashim), when asked about what he felt when he heard about his brother's diagnosis, seemed much more dispassionate. He said *"I felt sorry, very sorry for him, but I just had to accept it and go on".* This may reflect the differing intensity of a sibling relationship versus a marital one, as well as more general differences in men's willingness to express/experience intense emotions.

Another common reaction expressed by several carers in Kerala was a sense of betrayal. Since HIV is often sexually transmitted, discovery that a partner is infected with HIV can also involve discovery that the partner has been unfaithful sexually. Thus the disclosure represented a double blow—learning that a loved one has a deadly illness, as well as learning that this loved one has betrayed them. Carers verbalised feelings of betrayal, feeling let down, and being upset. Usha recalled her sense of feeling betrayed. *"He knew he had HIV, and kept it away from me and married me. Even when I noticed his health deteriorating he told he has a heart problem, so I feel betrayed".*

Another carer in Kerala said that this feeling of betrayal was accompanied by a new fear that she might be infected as well. Lizy said: *"...when I absorbed the reality that HIV had come in to our lives, I was very afraid for myself".*

In contrast, Ann, a HIV-positive carer from Scotland, spoke about her feelings of loyalty to her husband. Her husband had not contracted HIV through sexual activity.

Instead, he had apparently been infected when he shared a needle at a party. She said, *"He had no idea at the time that something done so thoughtlessly would have a heavy price to pay later ... so there's no question of betrayal, just our bad fortune if you like"*.

Carers in both settings also reported experiencing a sense of fate or karma. Sheena's response echoes the responses of several carers in Kerala. She said:

> *It is our karma that has brought HIV to our life. I know my husband well enough; he has not done anything wrong. Because my husband lived a simple way of life, it is hard for me to believe that he has HIV... we are going through this because we have to.*

Ann , a Scottish carer said that she felt weak in the face of destiny: *"I felt resigned to our fate; there was nothing we could do"*.

For the respondents in Kerala, learning of the family member's infection often brought on feelings of confusion. Since many of these respondents had a very limited understanding of HIV, they were often confused about the manner in which the virus was transmitted. Shiju, from Kerala, recalled that his reaction to his sister's diagnosis was one of complete confusion. He said: *"I had vaguely heard of HIV or AIDS or something like that, but when the doctor told us that she had HIV, I simply could not understand how she could get something like this ... I was totally confused"*. Bindu, Mary, and Ashim echoed Shiju's response of a feeling of confusion when confronted with the HIV diagnosis of their family member.

Three respondents (Sheela, Gangabai, and Sajini) in Kerala also reported feelings of hopelessness and despondency, as they realized that they were faced with an illness for which there is no cure and little effective treatment. Sajini recalled that the diagnosis of her husband came as such a shock that she felt utterly hopeless. She said: *"I felt as though a black curtain had fallen over my eyes and I felt totally lost... I felt as though I couldn't go on, as though my life had just stopped"*.

They also experienced fear of losses, which they saw as inevitable. Gangabai recalled with great pain the moment when she realised what her husband's diagnosis of an advanced stage of AIDS meant. She said: *"From one moment to the next my life changed. The thought that I would lose him cut through my chest"*.

The high level of stigmatization associated with HIV/AIDS in India also led the carers in Kerala to experience great fear that the illness would be discovered and that they would be socially ostracized and rejected as a result. The accounts of four carers (Mary, Bindu, Lizy, Savithri) revealed the shame they experienced, despite the fact that they themselves had done nothing wrong. Savithri recalled feeling ashamed of herself for her husband's illness. She said, *"Even though I know I have not done anything wrong, I feel ashamed ... I think it is because HIV is related to things like men and women's relationships"*.

A few carers in Scotland (Julia, Kate, and Ann) reported feeling fear that they would lose their infected family member. Kate recalled the terror she felt at the thought of losing her son. She said: *"I felt crippled at first when I heard about his diagnosis ... I was terrified of losing him"*.

Two carers in Scotland (Julia and Ann) spoke about the anger they experienced when they discovered the HIV status of their son and husband respectively. However the anger expressed was a vicarious kind of anger—anger that their loved one had lost something, a lost future. This was an anger that was motivated by unselfish emotions, which emanated from a deep sense of love. For example, Julia reported feeling angry when she discovered her son's diagnosis. She said, *"I felt a terrible anger towards life for doing this to him ... I guess I was angry with him too ... he had so much going for him"*.

Ann expressed anger on behalf of her husband as well, but it was mixed with anger at her own losses. When asked if her anger was self-effacing, she replied:

> *No, I was upset and angry on my behalf as well to an extent. Because we hadn't thought about children at that point, but I had kind of assumed that I would have them... we had planned to have a nice house with a walled garden, two cars and all the normal stuff. I felt that.... you know... I felt that... denied of these things, so I was upset*

> *for myself but I felt that there was not much point of feeling that upset when he was so unwell.*

Thus the accounts of the carers reflect a wide spectrum of initial reactions, which included shock, panic and confusion, fear of stigma, and fear of losing the loved one. The accounts of the carers reflect some of the unique circumstances related to the advent of HIV/AIDS, because of the stigmatising nature of this illness. Many of the carers had to deal with the double blow of learning that they might lose a loved one and also learning that the illness is one that is associated with severe social stigma and shame. They had to reconcile feelings that people with HIV/AIDS were blameworthy, with their own experience of a loved one with HIV/AIDS. This may explain the confusion expressed by a number of the respondents.

One of the key elements of the response of the carers was their level of awareness regarding HIV/AIDS prior to discovery of the illness in a loved one. For carers who were completely unaware of the threat of HIV/AIDS, news of a loved one's infection would be particularly shocking and confusing. For those who did have some awareness, the fear and shame associated with this epidemic would be brought home to them. This element of previous awareness regarding HIV/AIDS is reflected in the sub-theme described below.

Awareness of HIV/AIDS Prior to Discovery

HIV/AIDS is a relatively new phenomenon, which has a sweeping impact on the lives of those who are affected and infected by it; and yet, most of these carers came to the experience with little or no background knowledge. Therefore it was important for many carers in Kerala to talk about their awareness (or lack of it) regarding an illness with such huge ramifications, which was literally forced upon them. This was particularly evident in the fact that these carers wanted to clarify many of their concerns vis-à-vis HIV/AIDS and its treatment with the researcher.

The differences between Kerala and Scotland are particularly evident in regard to the carers' awareness of HIV at the point of discovery that a family member was infected. All of the Scotland respondents had at least a basic awareness of HIV and

AIDS, and had some general knowledge about how the virus was transmitted. Ann's remarks are representative, *"I knew all about HIV, and that is why I never imagined that it would be something that I would face"*. Similarly, Archie remarked, *"Since the mid-1980's in Scotland we've been exposed to a lot of information about HIV and AIDS"*.

In Kerala, however, the general level of awareness concerning HIV is much lower. Many (17, n=23) of them reported that they were completely lacking in awareness regarding HIV at the time they learned about the infection of a loved one. Bindu's remarks reflect this: *"I did not know anything about HIV at that time, now I know that these are some germs that can spread if you have physical contact with someone infected"*. Her remarks suggest that she still had a very limited understanding of how HIV is transmitted, which is a concern for one who is providing care to an infected person. Her lack of knowledge may well increase her risk of becoming infected herself.

Even those who had some information had only a basic understanding about HIV/AIDS. Maya and Shalini's questions to the researcher reflected this lack of awareness. Shalini asked: *"Are HIV and AIDS two different illnesses ... which one is worse?"* Maya asked: *"Do women get AIDS and men get HIV?"*

Beyond this lack of awareness in Kerala, there is also widespread misinformation about the way in which HIV and AIDS are transmitted and about the treatment available. The researcher spent a substantial amount of time in some of the interviews trying to clarify misinformation, such as belief in miracle cures available from the West. It was evident from the interviews that there was a general lack of awareness regarding HIV and AIDS. The need for further education and awareness runs as an undercurrent through much of this study. This need is further highlighted in the concluding chapter.

Another important element of the advent of HIV/AIDS in the lives of the carers was the process of becoming a carer. As can be seen from the sections above, many of the carers were shocked by the discovery of HIV/AIDS in a loved one and seriously lacked information about the illness. Nonetheless, they had to arrive at some sort of decision regarding the care of their loved ones, many of whom were already seriously ill. The next section deals with the route/course that led to them becoming carers.

How the Carers Became Carers

Once they learned that a loved one was infected with HIV, the carers began the process of becoming carers. For many of the respondents, this was not really a matter of choice, since there was no one else who was available to provide the necessary care. This was particularly true in Kerala, where there are often no alternatives to family caregiving when someone becomes severely ill.

In both settings, the decision to become a carer was often compelled by the circumstances or by feelings of love by the carers. They simply did not see any alternatives and thus took on the duties of caring as a matter of course. The accounts of a few carers in Kerala reflected this reality. Shiju, who was the carer for his sister, said:

> *She was too ill to look after herself and her children after her husband died, so I felt compelled to bring her to my home. At least here they will have a plate of rice to fill their stomachs.*

Archie, a carer in Scotland spoke of his commitment and love that compelled him to care for his HIV-positive partner. He said, *"There really was no question in my mind ... I knew that I would take care of him"*.

Despite the absence of choice for many of the Kerala respondents, a carer whose sister had AIDS reported making a conscious decision to provide care. Chandran spoke about his sister's heart-rending situation. He said:

> *Her in-laws literally threw her out from her sick bed on the day that her husband died. The police were going to take her to some hospice when I arrived ...there was no way that I would let her die in such a place.*

The accounts of a large majority (19, n=23 in Kerala and 4, n=5 in Scotland) of carers reflected a sense of duty and love towards their family member living with HIV/AIDS. This sense of duty and love seemed to be an almost visceral phenomenon, respecting no boundaries or contexts. In some cases, this was the love of a wife for her husband; in others it was the love of a mother for a son. These bonds of love seemed to override whatever fears the carer may have had for his or her own safety or reputation in a context of social stigma attached to HIV/AIDS.

Gangabai, the wife of a man with AIDS in Kerala commented, *"I feel that I belong to him and no matter what struggles I have to live through, I will look after him"*. Similarly, Kate, from Scotland who was caring for her son said, *"He is my son ... he is a part of me and no matter what befalls me, I will care for him"*.

The very real sacrifices that the carers made in order to provide care for their loved ones are among the most poignant aspects of the phenomenon of family caring. Without these sacrifices, many of those suffering with HIV/AIDS would be completely without care and comfort. Yet, surprisingly, very little attention or recognition is given to the carers themselves, who give so much and receive so little in the way of support.

Summary

Thus the first theme, on the advent of HIV/AIDS in a family, reflects the experiences of the carers as they first encountered the reality of HIV/AIDS in their lives. It includes the carers' discovery that the loved one had HIV/AIDS, their initial response to this discovery, their prior awareness of HIV/AIDS, and the process of becoming involved in caring for their loved one, often not as a matter of choice, but out of the circumstances in which they found themselves and because of their sense of love and duty that exists within the context of a family.

This first encounter with the reality of HIV/AIDS is important for the carers in a number of ways. First, the discovery of HIV/AIDS is remembered by many of the carers as a very traumatic experience, with great emotional significance as well as possible long-term consequences for the carers. Second, this time of discovery is an important point for intervention. Most of the carers had limited awareness regarding HIV/AIDS prior to the discovery, and thus they present a great need for education and counselling to help them cope with the emotional trauma and learn how to provide the necessary care. Finally, this encounter reflects the strength and commitment of the carers, who undertake the burdens of care out of a sense of love and duty. It is thus important for those who seek to help the carers to understand this crucial first encounter between the carers and the reality of HIV/AIDS.

Having explored this first theme, the next theme that is examined includes the varied experiences the carers encountered while caring for a family member living with HIV/AIDS. Because of the life-threatening, stigmatising nature of HIV/AIDS, the experience of caring can have an impact on many aspects of the carers' lives. This theme will explore these aspects in some detail.

The Experience of Caring

This theme concerns the reactions that the carers had to the burdens of caring. Many aspects of the carers' lives were affected by the burdens associated with caring for a family member with HIV/AIDS. Some of these reactions reflected the many tasks that the carers had to perform, such as the physical strain of lifting their loved one and performing other physical tasks such as bathing and cleaning, as well as the emotional tasks of helping the sick person to manage his/her feelings and other worries. Other reactions seemed to reflect the many uncertainties faced by the families, such as facing possible death as well as economic uncertainty and poverty. Finally, their accounts reflected the social burdens of stigma, marginalization, ostracism, and discrimination which they faced on account of their proximity and relationship with the cared-for person. To encompass these varied reactions, four sub-themes are included: physical reactions, emotional reactions, social experiences, and financial issues.

Physical Reactions

Providing care for a family member with HIV/AIDS often involves a great deal of hard, physical work. Particularly at the latter stages of the HIV syndrome, the HIV/AIDS-affected person may need assistance with nearly all physical functions, including feeding, dressing, bathing, toileting, and moving in and out of bed. Performing these duties can greatly increase the workload of the carer, who may also be called upon to work outside the home in order to support the family. Not surprisingly, the carers reported a number of physical reactions related to the physical demands of caring.

A majority of the carers (21, n=23 in Kerala; and 3, n=5 in Scotland) in both settings reported feelings of great tiredness or exhaustion. This reaction no doubt reflects the increased workload that they experienced, which could include trying to support the family financially as well as caring for the infected family member. Several mentioned the lack of time for themselves, as their days became filled with the many tasks that they had to perform. Although the carers in Kerala seemed to speak mainly of physical exhaustion, the respondents in Scotland spoke more about mental exhaustion. This may reflect economic differences in the two settings, as well as differences in the way that the carers experienced the strain and burdens of caring. Gangabai, from Kerala, said:

> *I come to the hospice every morning and help with his nursing, toileting, washing, feeding etc until evening when I go home. This affects me physically, I am exhausted at times ... but I keep going as I feel I have a duty to take care of my husband ... It is such a struggle.*

Sheela, a carer from Kerala, observed:

> *I feel dead tired and exhausted all the time, but I am committed to him, because he is my responsibility. Now he can't do anything, he is bed ridden – so I have to take care of him like a baby.*

In contrast, Kate, from Scotland, spoke about the mental exhaustion, saying, *"I am often just plain exhausted worrying about things ... I feel tired at the thought of things, even before I do them".*

Other reactions that were common in both settings included loss of sleep, appetite, and weight. These reactions, which are symptoms of depression as well as anxiety, could reflect the emotional stresses that the carers were experiencing. Meena, a carer in Kerala, recounted that she could not sleep because of her many worries:

> *...my worries about how I would manage everything ... Now he is dying, leaving us behind. I don't know what to do, where to turn to. He has become very weak, emaciated, has diarrhoea and high temperature, and severe coughs, I am struggling all the time.*

Julia, from Scotland recalled being unable to sleep and losing her appetite. She said, *"Whenever I get too stressed, I am just not able to sleep and eat a full meal"*.

Although carers in both settings commented on physical exhaustion related to performing duties of care for the HIV-affected family member, the respondents in Kerala seemed to be especially exhausted. These carers often had to carry out all of the tasks of caring themselves, with no formal assistance. In contrast, the carers in Scotland could rely on support from statutory social services and the National Health Service. This inevitably lessened the carer's physical burden. Ann spoke about this:

> *...when my husband was unwell we had district nurses come round to the house as he got a bit more unwell, he was over 6 foot tall, it became quite difficult for me to lift him and these two nurses came to help in the evening to help to put him to bed.*

Thus it can be seen that the caring process involved considerable burden at the most basic level—simple physical exertion. Most carers mentioned spending considerable energy and time on activities that directly impacted on the physical well being of the carers. The experience of caring is thus one of hard work, often with no respite for months.

The hard work of caring is made more challenging when it is undertaken in circumstances that are emotionally challenging as well. The next section discusses the emotional experiences reported by the carers.

Emotional Reactions

HIV/AIDS is known as a stigmatising illness that is almost always fatal. Thus the process of providing care to a loved one who is infected with HIV carries a number of emotional burdens as well as the physical ones. Carers could anticipate the decline and death of the person they cared for, and they also had to deal with the constant threat of social rejection, due to the stigmatising nature of HIV/AIDS. Caregiving is thus a tremendous emotional challenge, which can provoke a number of different emotional reactions.

Not surprisingly, the circumstances of caring for a family member with HIV/AIDS prompted many worries for carers in both settings. Feelings of anxiety and worry were very common, as the carers dealt with the deterioration of the infected family member as well as economic and other burdens. Ann recalled rather graphically the unvarying stress and anxiety she experienced as her husband's health began to deteriorate. She said, ***"It's always there at the back of my mind, most time it is on top of my mind ... AIDS has a way of putting you under a shadow that you never quite can come out of".***

Emotional pain was also a predominant reaction in both settings. The carers had to confront many painful realities, including the possible death of a loved one, the possibility of their own infection, and, in many cases, sexual infidelity. The accounts of Meena and Gangabai reflected the anticipatory grief as they saw their loved ones deteriorate in an AIDS hospice in Kerala. Meena said, ***"I have begun to prepare for his loss, but I do not know how I will live without him ... there is no one in this world whom I can call my own".***

Sajini and Bindu's accounts revealed their vulnerability in the face of HIV infection. Bindu's thoughts about HIV infection seemed to echo Ann's sentiment about AIDS throwing a shadow on the lives of carers. She said, ***"I feel as if this black cloud can burst on my head at any time, it keeps following me wherever I go".***

The accounts of three carers (Thusha, Leelavathi and Lizy) reflect the painful, helpless reality of sexual infidelity that the spouses of HIV-infected persons in Kerala experiences. The carers not only had to bear the humiliation of their partners' sexual infidelity, but they bore the additional pain of keeping silent over this on account of the ill health of their husbands. Thus the accounts of these women reflect the triple jeopardy they experienced. Leelavathi said, *"I cannot openly ask him if he has been unfaithful to me. I am after all his wife and I have to accept it because he is a man, and such things happen all the time"*.

For the respondents in Kerala (7, n=23) an additional emotional burden was the constant fear of rejection and isolation. These carers were unable to confide in neighbours and friends because they risked rejection by the larger community if the loved one's HIV status were known. Hence, the experience of caring was often a very lonely one. Sheela's touching account portrays the harsh reality of many carers in Kerala who live each day in the fear that they may be discovered and subsequently shunned by their communities. As discussed at some length in the methodology chapter, the researcher had to interview the carer in the night so as to protect her secret. She said:

> *If my neighbours were to know, then that would be like signing our death warrant ... it would be the end of us. I have read about one family being forced to flee because of this ... we do not want to live through such hell.*

It can be seen from these examples that the carers were deeply affected by the emotional challenges of caring. The particular nature of HIV/AIDS, with its sexual and stigmatising implications, adds to the burden of care imposed upon the carers. They had to undertake the emotionally challenging work of caring for a loved one in an atmosphere of threat, blame, and betrayal. Their already heightened worries about the welfare of the HIV-affected person were thus compounded. The social aspects of this atmosphere will be further explored in the next section.

Social Experiences

Because HIV/AIDS is a stigmatising illness, many of the social reactions reflect the negative stereotypes associated with the illness. HIV/AIDS first came to widespread attention as a disease of gay men, and it is often assumed that individuals who contract HIV have engaged in sexual acts that may be seen as immoral by mainstream society. The fact that many of those currently infected with HIV have worked in the sex trade or have used injecting drugs only adds to the association between HIV/AIDS and immorality. And when these assumptions are coupled with widespread ignorance about the transmission of HIV, the scene is set for severe social rejection and stigmatisation of those who are infected with HIV and those who care for them. The experiences of the carers in Kerala particularly reflect these circumstances.

Respondents in both communities mentioned experiences of stigmatization and discrimination, but these experiences were much more severe for the respondents in Kerala. Family carers from Kerala described this circumstance as "a living hell". They were subject to discrimination, isolation, ostracism, and marginalisation, as well as verbal abuse. Mary spoke about the sheer humiliation and isolation she experienced on a daily basis from her neighbours. She said:

> *Our neighbours close their doors and windows when we pass by and do not allow their children to come anyway near my house. Some neighbours have asked us to keep the doors and windows shut as the germs would spread through the air.*

Lizy recalled how her relatives behaved very badly when they came to know of her husband's HIV diagnosis. She said:

> *They won't come to our house; their children are forbidden from coming to our house. My husband's sister invited us for a house warming out of obligation, we felt assured that everything would be fine so we attended. We were served some drinks, but later I saw my relative throwing the glasses away when we finished drinking; this was very painful, it was adding insult to injury, it was very cruel.*

Experiences such as these highlight the widespread lack of basic knowledge about HIV/AIDS in Kerala. In addition to basic misunderstanding about transmission, members of the community often assume that any person who is HIV positive has engaged in immoral sexual behaviour. Savithri recalled how her neighbours shouted abusive words at her, when she went to draw water at the well. She said: *"They screamed hysterically 'you dirty woman ... lowest of the low, you are polluting our water, get out of here'".*

The widespread ignorance and fear of the populace in Kerala has contributed greatly to the hardship for the carers there. The need for basic education to increase the general level of awareness regarding HIV/AIDS is evident.

The problem of stigmatisation is even more acute because of the basic lack of privacy in many communities in Kerala. Privacy of home life and confidentiality of medical records is assumed as a given in western society, but in Kerala it was not uncommon for neighbours to intrude on "private" moments. Beyond this, it was not uncommon for medical professionals or others working in a medical setting to disclose private information to the larger community. Sajini said that her husband's HIV status was discovered by one of her parent's neighbours. The neighbour worked as an accountant in a pathology laboratory where her husband was tested. When the news about his status spread neighbours stopped coming to their house and stopped talking to them. She recalled how difficult it was for her parents. She said:

> *This led to increased tension in their house. Finally my parents sent word to me to say that we were not welcome in my family home. For the past 3 years I have not gone there. I think my family is afraid that they would be isolated and ostracised by the society due to my husband's condition. So they severed all ties with me; they don't visit me, nor do I. I ache to see them ... I have thought several times of visiting my parents; but I know that would lead to further tensions as my sister is about to get married and that can lead to disruption; neighbours would spread bad news.*

A particularly distressing aspect of the social mistreatment of the carers in Kerala was the misconduct of trained medical professionals. Sheela recounted the time when her husband was admitted in a multi-speciality hospital for a kidney stone operation. The doctor arranged for blood test before the operation and it proved positive for HIV. She said:

> *The staff panicked and spread the news in the hospital ... they treated us so badly. My husband was discharged and they asked us to go to the medical college hospital. He was very upset and has lost hope; he did not go anywhere, he has just returned home.*

The accounts of Sheena and Ann, carers from Kerala and Scotland respectively are discussed at some length as case vignettes later in this chapter. They further detail the insensitive treatment meted out to some carers in both Kerala and Scotland.

Despite widespread experiences of stigmatisation, there were exceptions in the accounts of the respondents. Gangabai, a carer from Kerala, found that her life had taken a complete somersault when her husband's HIV status was discovered by the community, resulting in them having to flee from their home. She spoke about the magnanimity of the doctor who visited the hospice where her husband was being cared for. He paid for her to travel with her child each day to the hospice and back and a little money for food too. She said, *"He is an angel who has been sent down to help us ... he is not an ordinary human being"*.

Although the respondents from Scotland did report some experiences of stigmatisation, some others also reported experiences of acceptance. Trisha recalled that when her daughter's diagnosis was first discovered by some of the neighbours, she was made to feel discriminated against by one person, but accepted by others. She said:

> *Yes, in a way I did feel very isolated ... A few years ago, when my next-door neighbour found out that my daughter was positive, she built a very high fence around her garden. She would not allow her son to play with my little grandchild. As a result my child played with all the other children around, and no one played with her child. She really had to rethink her ways.*

Ann, Kate and Archie spoke about the acceptance and positive support they had received. Archie said, *"I have had many positive, self confirming experiences ... friends who have understood and supported me and cared for me ... All kinds make the world"*.

It is important to highlight the fact that the impact of HIV-related stigma has lessened considerably in Scotland over the last decade or so. Some of the early accounts of people living with HIV/AIDS in Scotland reveal the fear, stigma and discrimination HIV-positive people experienced. This was further reinforced by the media which painted HIV as bringing gloom and doom and death and destruction. However, incremental changes in the treatment and management of HIV in the UK has brought about tremendous changes in the ways that HIV is perceived both by HIV-positive persons themselves and society in general. The introduction of free combination therapy by the National Health Service has created a paradigm shift, where HIV/AIDS is perceived as a chronic; manageable illness rather than as a terminal illness. This paradigm shift has been instrumental in lessening the fear psychosis that and resultant stigma and discrimination.

Moreover, the public health education campaigns by the governments and health boards have also helped stem the tide of stigma and discrimination against people infected with and affected by HIV. Equally the media has played a pivotal role by highlighting stories of HIV-positive people whose courage and determination have led to the creation of organisations for persons living with HIV/AIDS; and the development of policies and legislations that make discrimination on the basis of HIV/AIDS illegal. Also giving the HIV education campaigns a 'celebrity face' has helped create a greater awareness among the general populace to accept HIV as just another illness. It is important for policy makers and the media to appreciate the advantages of such experiences in reducing HIV-related stigma in a developing world context like that of Kerala as the stories of some of the carers in the present study portray the bitter experiences of stigma and discrimination.

The accounts of stigmatisation and mistreatment of the carers are particularly disheartening. The carers provide valuable services for HIV-affected individuals, which are often unavailable from any other source, yet they are often rejected and marginalised by the communities they live in. The need for further support and for recognition of the contributions of the carers is evident.

A further impact of stigmatisation that may not be immediately apparent is the effect it has on the economic well-being of the carers. The next section details some of the economic hardships experienced by the carers. These hardships were often directly related to the climate of stigmatisation and fear regarding HIV-positive individuals and their families.

Economic Issues

Economic concerns often played a major role in the experiences of the family carers in both settings. In cases where the HIV/AIDS affected person was the breadwinner, the family often faced severe economic hardship. In addition to the loss of income, there were concerns about the expense of medication and other treatments as well.

HIV/AIDS has a devastating economic impact on carers, especially in developing countries, where there are no financial safety nets or welfare measures in place. It is worth noting that the overwhelming majority of the carers (22, n=23) in Kerala had income at a subsistence level. The advent of HIV and AIDS puts an additional pressure on families that live at the subsistence level. Moreover, the burden is especially severe when carers are parents (Ferreira et al. 2001). Traditionally children have supported their parents in old age. Because of HIV/AIDS, these roles have been reversed; increasing numbers of parents are losing the support that they might expect to receive from their children but are also required to care and support their children and grandchildren due to HIV/AIDS. Caring for a family member living with HIV/AIDS put huge pressures on the carers—they must maintain an income, take care of the family member living with HIV/AIDS and take care of the children at the cost of their health and well being.

In both communities, carers noted that they received limited financial support from their extended family, and a considerable number (8, n=23 in Kerala and 2, n=5 in Scotland) reported difficulty finding and maintaining a job. Sheena, a carer from Kerala, recalled how they had no regular source of income; the limited income that they received from a few agricultural produce kept them going. She had tried to find work on several occasions, but was not hired because of her husband's HIV status.

She said: *"I would have been happy to do some domestic work if people were willing to employ me"*.

Gangabai's story echoes Sheena's experience: *"I tried to find a job, but nobody wants to employ me as they know about my husband, they fear I would also have HIV"*.

The accounts of four carers in Kerala (Shiju, Ashim, Santhosh, Usha) and one carer in Scotland (Julia) who could find work, reflected the role stress experienced by them, as they tried to balance work and caring responsibilities.

Shiju recalled the problems he experienced in finding time to do his job and to take care of his ailing sister. His account poignantly reflects the many conflicts that carers experience in their role. He said: *"If I do not work, I get no money and we would not survive ... but if I do not make the time to take her to the hospital and be with her, she will not survive"*. Julia's account also highlighted the difficulties of carers in finding and maintaining a job. She said: *"It is really difficult to balance things ... you are pulled in both directions"*.

For the respondents in Kerala, the process of caring often took place against a backdrop of extreme financial hardship. All 23 respondents reported a loss of income, and some experienced severe poverty and hunger as their resources were exhausted.

Gangabai, who became destitute after the community discovered her husband's HIV status and subsequently was outcast recalled with great pain her inability to provide for her child. She said:

> *What has affected us most is the lack of money and the poverty. My child has not eaten anything for the past day ... he is hungry; the doctor gave me some money on my last visit ... I hope he would give us something today; or we will be without any food.*

Gangabai's account reflects how she experienced even greater hardship as the result of stigmatisation, because she lost her job when the HIV status of her husband was revealed. She said, *"I worked as a domestic with a rich family; they came to know that my husband has AIDS and they asked me not to come from then on ... so I was lost in all ways"*.

Usha lived under the shadow of fear that she would lose her job if the employer got to know that her husband has AIDS. She said:

> *I have never worked outside the house; I am just managing now by working as a domestic ... the family I work for do not know that my husband has AIDS. I told them he is in this place for alcohol related treatment. This is a charitable hospice and accepts people with different problems. I am worried they would come to know somehow and that would be my end; they will throw me out.*

At the same time a large number of carers in Kerala (15, n=23) experienced a loss of income, they also experienced an increase in expenditures as they tried to pay for medical care for the infected family member.

Sabira, whose husband used to work in the Gulf, recalled how the medical expenses were eating into their limited savings. She said:

> *It is very difficult to manage the medication ... he can't work now. The medicines are very expensive ... we were just managing until now ... but his deteriorating health has put a huge pressure on our finances ... we have an outstanding loan taken when he was going to the Gulf ... I don't know how I'll repay.*

Several others echoed her worries. Chandran, who cared for his sister, said, *"An HIV-positive person is a very large financial burden on the family"*.

It is interesting to note that in the context of Kerala some carers (Sheena, Gangabai, Maya, Bindu) reported that their husbands lost their right to inheritance of parental property once their diagnosis was revealed. Maya's experience is similar to the experience of all these carers. She said: *"I was so shocked that they pulled the ground below our feet from under us ... at a time when we were so devastated, they made sure that we would be ruined"*.

Many carers in Kerala (15, n=23) reported receiving no financial support from any source. The few carers received some financial support from their extended families. It must also be recalled that there are no welfare benefits or public funds available to carers in Kerala.

Although the family carers in Scotland were better off financially, they still reported experiences of financial distress associated with the process of caring for the infected family member. Kate said that caring for her son with AIDS, entailed many unexpected expenses. She said, *"You just can't plan enough ...there is always a new bill to pay or something that goes towards his care, that you're not planned for ... so it's kind of difficult at times to keep everything running".*

However the respondents from Scotland did have an additional resource—the possibility of financial support from the state. Nonetheless, all the respondents in this study reported that this assistance was minimal.

The economic burdens of providing care added greatly to the hardship experienced by the carers, particularly in Kerala. Many of these caregivers were already poor before the discovery that a family member had HIV/AIDS, but they faced increased poverty and hardships and in some cases destitution afterwards. The combination of factors—limited time to work, limited resources for obtaining medical care and medicine, and widespread stigmatisation—combined to create incredible stress for the carers. The high level of anxiety and despair reported by many carers is quite understandable in this circumstance. The worldwide statistics regarding the relationship between HIV/AIDS and poverty are illustrated here in harsh detail.

Summary

This theme has illustrated the physical, emotional, social, and economic impact of caregiving for a family member with HIV/AIDS. It has shown how the realities of providing care impacted all of these areas, creating a number of difficult burdens for the carers. For many of the carers, the process of providing care was a constant struggle—against physical exhaustion, overwhelming worry, social ostracism, and financial ruin. Widespread ignorance and misunderstanding regarding HIV/AIDS only served to heighten this struggle, creating further burdens for carers who were already facing extremely difficult conditions. The willingness of these carers to go on and to continue to cope each day is truly impressive in the face of these burdens.

As might be expected, the many challenges had their impact on family relationships and dynamics. The next theme focuses on the various impacts that caring had on family dynamics.

Family Dynamics in Caring

This theme concerns the effect of caring on family relationships and roles. It includes a discussion of changes in family roles and relationships, as well as subthemes that focus on communication, sexual relationships and reproduction, and issues related to children.

According to Brown and Powell-Cope (1991), the sine qua non of family caring is a relationship between two persons. Generally these two individuals know each other well before the onset of HIV/AIDS. Nonetheless, these individuals often find that the new roles of carer and cared-for have forced them into uncharted territory. They suggest that these individuals must understand each other on new terms, rethinking their roles and renegotiating the give-and-take of their day to day lives. The carers in this study reported a number of experiences that illustrate this phenomenon.

Many carers in both contexts suggested that the advent of HIV/AIDS and the burdens of caring had an effect on their family relationships and behaviour. However, a few respondents in Kerala (5, n=23) and Scotland (2, n=5) indicated that the family dynamics were relatively unchanged. As a beginning, the section examines the reactions of those who said that their relationships did not change.

Two carers in each context said that their relationships with the cared for family member did not change, because the family member living with HIV/AIDS was their child. Two carers in Kerala, Kumaran and Kanaran, and two carers in Scotland, Trisha and Kate, had children who were HIV-positive. Kumaran said: *"Our* *relationship cannot change. She is my daughter and I am her father, so how can anything change"*.

Kanaran said: *"Since his accident we have been looking after him, but that has not changed anything ... we love him and take care of him like we would have, even if he was well"*.

Similarly, Trisha said: *"I guess this is one relationship that really cannot be altered. The relationship between a mother and daughter is so instinctive"*. And Kate said: *"He is my son; I do not think something like this can change our relationship"*.

Three carers in Kerala (Bindu, Maya and Savitri) felt that their relationships with their husbands had not changed with the event of HIV in their lives, because they were bound by their marriage vows to continue to be dutiful wives. Savitri's words reflected their thoughts. She said: *"I married him for whatever he has or does not have, so it is my duty to remain the same and take care of him now"*.

It appeared that those who reported no change in the relationship were thinking in terms of their roles as spouse or parent. For them, the duties involved in fulfilling these roles meant that they would not change their relationships with the HIV/AIDS-affected person, regardless of the hardships they experienced. For them, assuming the burdens of providing care were no more than what was expected of them as a spouse or parent.

A few carers in Kerala (3, n=23) and one carer (n=5) in Scotland reported increasing tension, anger and resentment in their relationship with the HIV/AIDS-affected person. Usha's husband worked in Bombay. She spoke about the anger and resentment that she felt towards her husband for lying to her about his health. She said:

> *I feel betrayed. He knew he had HIV, and kept it away from me and married me. Even when I noticed his health deteriorating he told he has a heart problem, so I feel angry and that causes a lot of tension now.*

Thusha's anger too seemed to arise from the fact that her husband was unfaithful to her, while he was in Bombay awaiting his visa for the Gulf. She said, *"I feel anger and frustration with him for bringing this to us ... I know we would not have had this problem if he had not spent that much time in Bombay"*.

Julia, a carer from Scotland, spoke about her feelings of resentment and anger at her son for ruining his life. She said:

> *I get really angry when I think about what he has done to his life ... I resent him at times for giving me this terrible hurt and pain, but in my saner moments I know that I should not feel this way.*

Still others, Gangabai, Sheela, and Sheena from Kerala and Ann from Scotland, noted an increased sense of togetherness and commitment, as they struggled to manage the burdens brought by the advent of HIV/AIDS in their lives. Sheena, who was disowned by her family and ostracised by her community, said, *"We feel much closer and stronger together as we have really nobody now to relate to. I can do anything for him"*.

Gangabai, whose husband's illness left them destitute, spoke with great commitment and feelings about her husband. She said, *"I love him more now, when he is dying ... I feel that I belong to him and I will take care of him no matter what it does to me"*.

Ann spoke rather poignantly about caring for her husband. She said:

> *Our relationship was very good in lots of ways, but taking care of him has made our relationship much stronger. I feel totally committed to caring for him. I think a lot of it is very heart-rending, but the new togetherness is beautiful.*

A number of Kerala respondents reported difficulties in relationship to the roles played in the family. In some instances, the circumstances required a change in roles, as the head of the household became less able to function and had to depend more on the carer for daily decision-making. Three carers (Usha, Geetha and Savithri) all spoke about how their husbands were the main decision makers in their homes before their diagnosis of HIV. Their accounts reflected how the illness and debility of their husbands, who were the heads of their households, changed the role and power relationships between them and their husbands. Many of these carers belonged to families where traditional family roles existed prior to the advent of HIV/AIDS, and that change was at times confusing and difficult. Geetha said:

> *Before he became sick he would never consult me about financial matters, he never asked me if I wanted to buy something, he would just do everything by himself. But now I do not know what to say sometimes, because he asks me to decide about everything ... even very simple, simple things.*

Dealing with HIV/AIDS brought sweeping changes to the family lives of most of the carers, as the HIV/AIDS-affected person became unable to fulfil his or her previous family roles. These changes were often confusing for the carers, particularly those who had been raised in a context of very traditional family roles and relationships. Uncertainties related to the changes in family roles contributed to the anxiety and distress of the carers, who were forced to adopt new patterns of behaviour and relationship. Thus another unanticipated burden was added, further straining the coping resources of the carers. As will be seen in the next section, the carers were not always able to talk about these changes with the HIV/AIDS-affected person.

Patterns of Interaction and Communication

With so many changes taking place, and with serious threats to the economic, social, and emotional well-being of the family, the carers and the cared-for had many issues that they needed to discuss and resolve. These issues often represented uncharted territory, as the carers and the cared-for had to face things such as sexual infidelity, social rejection, and impending death of the cared-for person—issues that many had never discussed before. The families often faced isolation as well, due to the climate of social ostracism in which they lived, so the carers often had no one apart from the HIV/AIDS-affected person to talk to about their concerns.

Given these circumstances, it is not surprising that the issue of communication arose for many of the carers. Communication was frequently mentioned as an issue by the carers in both Kerala and Scotland. Some carers in Kerala (10, n=23) and a majority of carers (4, n=5) in Scotland noted that they were able to be open and frank in communicating about the many struggles that they faced. Lizy's account reflected the experiences of several others in Kerala, as well as the account of Ann from Scotland. She said:

> *We share our thoughts and emotions much more freely now ... There are no problems between us; we feel like sharing things more now, because we do not know how long we have together and where life will take us.*

Archie also commented about the openness of his communication with his partner. He said, *"We had a lot of things to share, with all that was going on ... we were really listening, and that's happening a lot more these days".*

However, for some carers in both Kerala and Scotland, the circumstances seemed to increase their difficulty in communicating, especially about emotions. Leelavathi, a carer from Kerala, whose husband had lived away from her in the Gulf for the major part of their married life, said:

> *I feel as though there is a wall between us, which I cannot seem to cross ... when he was here for only 2 months in a year, we had things to talk about, but now I do not know what to say.*

Julia spoke about the difficulties she experienced in communicating her deepest feelings with her son. She said:

> *I am not happy about it ... I would really hope that we could overcome this ... it's as though the pain or anger or some kind of negative emotion gets in our way of really saying what we are going through.*

The great intensity of feelings and the lack of free time for discussion no doubt contributed to the strain on communication for many of the family members with HIV/AIDS and their carers. They had a great deal to resolve, but they were often unable to do so. The lack of the ability to resolve many difficult issues was one more source of stress for many of the carers.

Sex and Reproduction

A HIV/AIDS diagnosis has special emotional significance for female carers in the area of reproduction, sexuality, and childcare. Sherr (1991) points out that one of the most poignant physical effects of HIV is the possibility it has of crossing the placenta and infecting the foetus, that is, vertical transmission. The presence of HIV therefore meant that many of the female carers were facing the loss of the opportunity for motherhood, as well as the loss of the HIV-affected person.

The decision to conceive a child or to avoid conception in the presence of HIV is a complex one; it is often not totally within the control of the female carers. Decisions about motherhood are not taken in vacuum (Hankins, 1997). All societies, especially developing ones, accord status and respectability to motherhood; thus the loss of childbearing is not to be taken lightly. The experience of childbirth, which generally stirs feelings of hope, life, and new beginnings, is coupled with the notion of illness, death, fear, and uncertainty in the context of HIV infection. Thus issues related to sex and reproduction loomed large for some of the carers in this study.

A few carers (2 carers from Kerala and 1 from Scotland) reported that the discovery of HIV meant that they would not be able to bear children, for fear of infecting either themselves or their prospective child. This loss of motherhood was often difficult and painful. Savitha said:

> *I think what I feel most bad about is not being able to have children ... the reason for taking birth as a woman, is to experience motherhood and that only has been snatched away from me.*

Shalini (a carer from Kerala) reported great feelings of ambivalence in relation to having a baby. She spoke about her desire to have a family coupled with a deep fear of infecting the child and herself. She said:

> *I feel caught up between both things ... on the one hand I feel that there is no life without a child and on the other I am so scared of getting infected and infecting the child ... I feel so lost when I think of these things.*

Women who are positive themselves face the crucial problem of uncertainty in relation to reproduction (Pierret, 1992). Ann's experience reflected the reasons for positive women wanting a child that included a desire to experience motherhood and a desire to enhance her gender self-image. Ann commented, *"It's a sharp, painful feeling because you really want a baby but you don't have one and you know that you're probably not going to have one."* She also noted the feelings of lost womanhood, as sexual and reproductive options were greatly curtailed. She recalled:

> *I don't think we should look at women as purely reproductive systems, but I think that there is a lot of stuff in relation to childbearing and being a woman that matter when you and your husband become positive.*

Thus reproduction became yet another difficult issue for carers and cared-for.

Issues Related to Children

Carers who were parents found themselves facing a number of issues related to caring for their children. Some had to deal with the very painful question of who would care for their children if both parents were lost due to HIV/AIDS. Others faced issues related to more immediate needs of the children, such as the lack of time for parenting. These issues added to the complexity of the problem of caring for a family member with HIV/AIDS.

Many of the carers in Kerala were the parents of young children, and it was they who mentioned concerns about the welfare of their children. Although three of the carers in Scotland were parents, their children were adults; thus, issues related to children did not emerge from their accounts.

Sheela, Lizy, Sheena, and Shalini spoke about their fears that if they were to be infected with HIV, their family faced the real possibility that the children would be orphaned. Sheela said, *"I often wake up in the early morning with palpitations thinking about this ... worries and thoughts about who would care for my children keep going round in my head."* Given the atmosphere of stigmatisation and social rejection of anyone close to a person with HIV/AIDS, the concern for the welfare of the children was acute. These parents could not reasonably expect that extended family members or members of the community would step forward to care for the children, due to widespread fear that the children would also be carrying the virus and may infect others.

Other issues concerned the ways that they parented their children. Gangabai spoke about her feelings of overprotection for her child. She remarked, *"I am so scared to leave my child even for a few minutes ... I take him wherever I go"*. Gangabai experienced the trauma of being shunned and literally thrown out of her home. As a result, she was destitute and lived in a hut away from her home. It seemed only natural for her to fear that some further harm would come to her or her child.

Sabira found that it was very difficult to find time for her children, due to the time-consuming tasks of caring for the HIV/AIDS-affected family member. The carers often found themselves struggling to balance the needs of their children with those of the ill family member, as well as the need to seek or maintain employment to support the family. Thus the consequences of HIV infection reached into the next generation, where the children were affected by the limited energy and availability of their parents.

Yet another dilemma was communicating with the child about HIV itself. Because of the danger of social ostracism, the HIV status of the infected person had to be kept secret. This raised difficult issues for Sheela. She said, *"One of my children goes to school now, but, we have not told them, in case they tell anybody about it ... that is enough for the people here to chase us out".*

Summary

This theme, concerning the effect of caring on family relationships, shows some of the complexity of the problem of HIV/AIDS. Once a family member has become infected with HIV, many aspects of family life are affected, and the carers must cope with a set of new dilemmas related to changing family roles, communication, sexuality and reproduction, and caring for children. It is thus not surprising that so many carers report feeling overwhelmed and exhausted; they are managing such a plethora of issues and concerns. Authors such as Kristin Sydnes (2001), Nishimizu (2002) and Fréchette (2004) have commented that HIV/AIDS tears at the very fabric of society. The accounts of the carers regarding the impact on their own lives and on their family lives provide ample illustration of the insidious effect of HIV/AIDS, and of the way it undermines one of the key elements in society—that of the family.

The next theme reflects an issue that was raised by only a few of the carers—the problem of being a carer and being HIV-positive oneself. Such themes are appropriate in a grounded theory approach, where the goal is to uncover all of the different aspects of a phenomenon, not just those that characterise the majority (Glaser & Strauss, 1967). And, as is discussed below, it is likely that some of the carers in Kerala would have expressed this theme if they had been aware of their HIV status.

Carers Who Are Positive Themselves

One somewhat unique theme concerned the effect of being a carer and being HIV-positive oneself. This theme was somewhat exclusive, and it illustrates the value of an open, grounded theory approach (Glaser & Strauss, 1967), which allows for the emergence of distinctive phenomena. When designing the study, the researcher had not specifically planned interviewing carers who were positive themselves; however, it is probably inevitable that some of the carers would be HIV-positive, given that so many of them were sexual partners of the HIV/AIDS-affected person and HIV/AIDS is sexually transmitted.

The theme emerged from the researcher's interviews with two carers in Scotland. Archie (who was caring for a same-sex partner) and Ann (who was caring for her husband) were the two respondents in this study who were HIV-positive themselves. They spoke about the affective and social aspects of being HIV-positive and caring for a HIV-positive person. The process of providing care for someone with HIV/AIDS when you yourself are also infected raised a unique set of issues.

Both Archie and Ann spoke about how the decline in the health of the HIV/AIDS-affected person affected them. It appeared as though the decline in the ill family member they cared for could be seen as a foreshadowing of their own decline. Archie said:

> *My partner has been ill, he is starting to realise that he may not be here very much longer ... I guess his feelings echo through me and I wonder about my own health and how long it will be before I am at where he is now.*

Ann expressed feelings that ran in a similar vein. She recalled, *"Caring for my husband and being positive myself have put my own health and mortality in to sharp focus"*.

Ann also spoke about the predominant issue of grieving that she and her husband experienced. She recalled the intensity of their feelings of pain and loss at the thought of being separated from each other. She said:

> *At times we feel very miserable for ourselves... we grieve for things that we can't have, what we wanted... what we liked, but most importantly for what it could have been if only HIV had not crossed our paths.*

She also spoke about her feelings of forgiveness for being infected by her husband, saying, *"I bear no grudge or anger towards him. Life dealt a very cruel blow to us both and I cannot but forgive him for something that he did without giving much thought to"*. Finally, she mentioned the tremendous support she received from her family of origin. This is discussed at some length in the next section on informal support.

Being positive and caring for a family member living with HIV/AIDS can have a unique impact on the mental health of the carer. The carer is likely to deal with serious health problems in the HIV/AIDS-affected person, knowing that they may have similar problems themselves in the future. The experience thus seems likely to promote particular anxiety and anticipatory grief, as well as other emotional concerns. This aspect will be further highlighted in chapter 8.

The question may arise as to why none of the carers in the Kerala sample reported being positive themselves. This was largely due to the fact that few of them had been tested, although it does seem likely that a good number of these carers might be infected with HIV. When the researcher asked carers in Kerala who were the wives of the HIV/AIDS-positive persons being cared-for whether they had been tested for HIV themselves, all of them with the exception of three replied in the negative.

These three carers (Sabira, Geetha and Gangabai) spoke about the immense relief they had experienced on receiving a negative test result. Gangabai recounted her renewed faith in God. She said, *"I have always had faith in God, but now I have become more devout"*. Geetha said that her negative result had provided much hope and reassurance to both her husband and herself. She recalled, *"When my result came back negative, it was as if a heavy weight had been taken off from over our heads"*.

However, 14 of the 17 wives in the study reported that they had not taken the test and were not likely to either. Their reasons for not being tested reflected a number of interesting issues.

One issue that arose was the fear of losing hope. A number of carers mentioned that they did not want to be tested because they could not face the despair they would experience upon learning that they, too were HIV-positive. Usha's response to the question of whether she would consider an HIV test echoed the many voices of carers from Kerala in this study. She said:

> *I haven't been tested for HIV; I feel very weak and exhausted these days. Maybe this is due to the stress of caring for him. Emotionally I can just hold on now, but if a test proves positive, I would lose hope and the will to live. I am afraid to go for a test now.*

It is poignant that these carers had to live in fear when perhaps they did not need to, because they might still be HIV-negative. They seemed to have a superstitious attitude about being tested, perhaps fearing that seeking the truth would doom them to be HIV-positive themselves. So they chose to continue living in doubt. Knowing that they were HIV-negative might have motivated them to remain that way and care for themselves a little more. By not getting tested, the cloud of worry and anxiety was always over them.

It should be remembered, however, that being tested in Kerala was not the same experience as being tested in Scotland. For one thing, none of the carers in Scotland had to worry much about the results of the test being made public, while the carers in Kerala had ample evidence that their test results might not be kept confidential by the medical providers in their community. This failing of the medical system in Kerala can be viewed as an important element in keeping many of the carers from getting accurate information about their own HIV status. Beyond this, it should also be noted that the carers in Scotland were offered supportive counselling and assistance along with testing, so that they were better able to deal with the results of the test. Such services were completely absent in Kerala.

Another reason for not being tested seemed to be a kind of fatalism. Shalini and Mary both appeared to have been resigned to their fate. Mary said, *"I have not taken an HIV test ... I used to fear about transmission to myself, now I have no such fear. If this has to happen, this will happen".*

Two carers (Savithri and Thusha) said they had not been tested because they were unable to afford the test. Savithri commented, *"I would rather use that money to buy some good food for my husband".* Her comments reflected the level of commitment and self-effacement of some of the carers, many of whom were too focused on the needs of their husbands to consider their own health.

This theme again reflects the complexity of the problem of HIV/AIDS. Because HIV is transmitted sexually, it creates a circumstance in which a number of the family carers, who are spouses or partners of the infected person, are likely to be infected themselves. This added concern heightens the stress and devastation brought to carers as they try to meet the needs of the HIV/AIDS-affected person. Even for those who were not tested, the stressfulness of caring is heightened by the lack of knowledge about one's own condition, and the fear of knowing the truth. The sharp differences between Kerala and Scotland are particularly evident in this theme.

The next two themes explore the resources available to the carers. Again, the sharp differences between Kerala and Scotland are evident. Informal support networks will be discussed first, followed by formal support systems.

Informal Social Support Networks

Social support is a significant element in caring for a family member living with HIV/AIDS. Having someone to talk to, to share burdens with, and to provide practical support can greatly alleviate the stress of providing care for the HIV-affected person. Such support can be provided formally, through organized programmes connected with the health care system, but more commonly, such support occurs informally, through neighbours, friends, and others who are experiencing similar burdens. With limited formal support options available in many settings, carers have to rely increasingly on informal networks. However, availing this resource is often fraught with the difficulties, due to the stigmatising nature of HIV/AIDS.

The accounts of the carers revealed that the majority of them had limited social support networks. Social support networks can be conceptualised as patterns or webs of social relationships that are crucial in providing support to individuals. How a person lives is largely dependent on how that person is tied into the larger web of social connections (Freeman, 2002). A social network can also be defined as "a specific set of linkages among a defined set of persons" (Mitchell, 1969, p.2). Srinivas and Beteille (1964) point out that social networks enable an understanding of the linkages existing between different institutional spheres and between different social groups.

The burdens associated with providing care for a family member with HIV/AIDS created a great need for additional social support, yet ironically for most of the carers in both Kerala and Scotland, this support was not forthcoming. The reasons for this lack of support were complex.

The stigma and fear associated with HIV/AIDS seemed to create a barrier that either prevented the carers in Kerala from asking for support or kept them from receiving it. This was the experience of the majority of the carers (21, n=23). Sheena's account particularly reflects this. She spoke of how she was totally cut off from her family and friends, and had absolutely no social support to fall back on, because of the social stigma that HIV/AIDS carried with it. She said:

> *My family have stopped all contacts with me, because they feel we dishonoured them. They themselves have had great trouble from the community; they used to sell milk to the local shop, who have now stopped buying milk from them. They even asked my mother to undergo a HIV test ... My family is more afraid of what their neighbourhood would say about them, ... we need a community to live in, and support from each other, and family support is very vital, but my family gives importance to the society: what the society think and say ....*

Additionally for the carers in Kerala, informal support was extremely difficult to come by. The majority (19, n=23) reported receiving no support from any source - family of origin, family of affiliation, friends, neighbours, or community leaders. Shalini recalled how she begged of her sister-in-law to baby-sit for her child while she was away in the hospital with her ailing husband. She said:

> *His own sister has become so heartless that she denied my 3-year-old shelter for 2 days. She said she was worried about what her neighbours would say if they discovered. I think she was also worried about my child having the illness and infecting them ... so I had to take our child to the hospital, where there is no place to sleep or even sit properly.*

There were two exceptions in Kerala where the carers were parents of the HIV-positive persons. Both parents were fathers, and they spoke about the support they received from their other children. Kanaran, who cared for his son who was HIV-positive and recovering from a road accident, said that this support kept him and his wife going. He said:

> *My children come and help us in whatever way they can—money, taking him to the doctor, comfort. We do not know how other families manage where their children do not help out, we would have been just finished without our other children.*

Kumaran echoed similar sentiments when he spoke about how he cared for his daughter and grandchildren. He said:

> *Without the love and support of my family, especially my other two daughters and their husbands I would have found it very difficult to take care of her. My daughters treat the children like their own, so there is no problem. This gives a lot of peace to my ailing daughter.*

Interestingly, two carers in Kerala, who were providing financial and other material support to their siblings in a hospice, stated that they did not feel the need of social support. These carers were living with their own families and their support to the HIV/AIDS-affected person was more indirect in a way, so perhaps these carers were less directly affected. Hence when the researcher asked them about social support they said that they did not perceive it as particularly important element in the caring process. This was perhaps because they had no need of it. Ashim's brother was in the hospice, with advanced AIDS. He did not seem to appreciate the significance of social support. He said, *"I come and visit him and do what I can for him, because he is my brother, what do I need support for, I am just doing my duty... I have my own family"*.

A few respondents mentioned limited support that they received from missionaries in Kerala, who were often quite reluctant to become involved. Santhosh explained how the missionaries themselves were under great pressure from the community to close down the hospice. He said:

> *As long as the missionaries were running this home for destitute people, the community had no problem with them. Now they are often forced to take in people with AIDS and the community are protesting against it. A few days ago they held a demonstration outside the hospice demanding them to shut down - so you see their hands are tied also.*

Although the carers in Scotland seemed to fare somewhat better in terms of informal support, they still reported a range of responses in relation to support networks. The majority (4, n=5) mentioned strong support from family of origin. Ann recalled how after a few months she and her husband shared the results of their HIV tests with her parents and her mother-in-law. She said:

> *I told my folks and they were really surprised, they were really shocked ... not in a bad way, because they had just not thought that would be something that they would really have to deal with .... So they were shocked, but they were really supportive. They were really good and didn't have any kind of bad reaction, didn't say anything bad about my husband. They said is there anything we can do and that kind of stuff. And I didn't tell my sibling till six months later, and it was kind of the same, shock and surprise and sadness, just concern*

> *and willingness to help. But my family were fab, really great support through everything.*

Ann also mentioned the lack of support they received from the family of affiliation. The reaction from her mother-in-law (family of affiliation) reflected a limited support and understanding. She recollected:

> *When my husband's mother was told, she found it rather difficult to cope. Her reaction was 'did he sleep with a prostitute?' which was rather offending ... but you know in-laws are not your family.*

Kate spoke about the importance of receiving support from her sister. She said:

> *Since I have started caring for my son, my sister visits me more often and offers me whatever support she can ... on many occasions I have felt sustained by her support and I know today that if I am strong, it is because of her unstinting support.*

Informal support networks can be an invaluable source of tangible and intangible support for family carers in most circumstances, but the unique dynamics of the HIV/AIDS epidemic have led to limited availability of such support for many family carers. The negative stereotypes and stigma associated with HIV/AIDS have made such support much less forthcoming. Individuals who would ordinarily provide support are reluctant to do so, out of fear that they will become infected or will be subject to the same blame and rejection that the HIV/AIDS-affected person experiences. This creates a crisis situation for many carers, particularly in impoverished areas, where there are few organised support services to compensate for the lack of informal support. The next theme deals with the availability of more formalised support systems.

Formal Support Services

Another possible source of support for the family carers is the more formalised support coming from governmental and non-governmental organisations (NGOs), some of which have been created especially to deal with various aspects of the HIV/AIDS epidemic. Such organisations could conceivably be a valuable resource to carers, providing information, supportive counselling, and even respite care and other material aid. The system for providing medical care could also constitute a formal source of support, providing services to help the carer perform the necessary tasks of care.

Such support can act as a buffer to the informal support networks. When carers have limited resources, the formal support system could help them to manage the problems associated with caring and could even help them to locate and access more informal sources of support. However, formal support systems are often lacking, particularly in developing countries. The contrasts between the two settings in this study are particularly strong in this area.

The carers in Kerala faced a remarkable lack of formalised support services of any kind. There are no formal services or organisations for the much needed psycho-social support of carers of persons with HIV/AIDS. As discussed in chapter 3, it is important to highlight that the few NGOs that do work in the field of HIV/AIDS in Kerala, are primarily for HIV-positive persons themselves.

In a personal conversation with the Director of *Prithyasha Bhavan* (AIDS Hospice), Kannur, Kerala (on February 21, 2001) the researcher was told that the purview of the NGO's generally extended itself to counselling for persons with HIV/AIDS, general awareness-building, and condom distribution. Moreover, there were no organisations in place that extended any services directly to the carers of family member living with HIV/AIDS. He believed that there was a paucity of resources, and a lack of political commitment.

The medical care system in Kerala is also very limited in the support that it offers. The public health care system in Kerala is generally free or charges a very nominal rate for medical prescriptions, but this system is overstretched and poorly resourced; hence it is rather limited in its scope for delivery of health care to persons with HIV/AIDS. At the time of the study it was unable to provide much beyond diagnostic services.

The limited services provided by both governmental and non-governmental organisations in Kerala were urban-centred and therefore often very difficult for persons in villages to access. Moreover, these services were primarily for the HIV/AIDS-infected person themselves. Sheena spoke about the time and effort she and her husband had to make to be able to get a listening ear from the Counsellor in Thalassery, which is a town in the Kannur District of Kerala. Although, the service was aimed at her husband, she suggested that she too was able to garner some support from this. She said:

> *We need to leave early in the morning to be here before noon, but it helps us to talk about our problems with the Counsellor because we have no one else who we can talk about these things. By the time we get home it is nearly nightfall.*

A large majority of carers (18, n=23) in Kerala spoke about similar issues. Chandran spoke about the problems he faced as a carer for his sister living with HIV. He said:

> *It takes us over 2-and-a-half hours to get to the nearest District Government Hospital. We need to be there before 8 in the morning to get a token to see the doctor ... often it is late afternoon when we get to see the doctor ... the doctor writes all expensive English medicines which we have to buy from the town. They are too expensive...*

A few carers spoke about the apathy of governmental staff in providing support to their family member living with HIV/AIDS. Kumaran spoke about the difficulties he and his HIV positive daughter experienced in meeting a Counsellor in the Government run hospital. He said:

> *Over the past year I have made several attempts to see the Counsellor for some information and to seek assistance but we have never managed to find him in his office. We are always told that he is away.*

This experience of the carers was also encountered by the researcher, who tried on several occasions to obtain an interview with the HIV/AIDS Counsellor in a District Government Hospital.

In another personal conversation with Dr Thobias, a homeopathic doctor at Amala Hospital, in Thrissur, Kerala (on March 2, 2001) the researcher was told that although the State government is spearheading the fight against HIV/AIDS through its AIDS Control Society, it operates only at a macro level and does not have any impact on the lives of the many thousands who live in villages in stigmatising, resource-poor environments. He highlighted the paucity of services and absence of policies for the welfare of persons living with HIV/AIDS. He believed that given the situation, it would be years before carers of persons living with HIV/AIDS were given any recognition. These thoughts were similar to those communicated during the researcher's earlier meeting with the Director of *Prithyasha Bhavan,* who said that it would be years before a voice is given to the needs of carers, who live in a culture of silence, with a day-to-day fear of stigma, discrimination, and ostracism by their own communities.

While private medical treatment for HIV and AIDS, such as antiretroviral therapy was available, it was too expensive to be affordable for the participants in the study. Only four carers in Kerala were able to afford allopathic drugs for the symptomatic relief/treatment of HIV/AIDS related illnesses. Sabira said:

> *Because my husband worked in the Gulf for some time, we are able to buy him vitamins and other medicines for his lung infection. The doctor in the private clinic told us that there are some very good medicines to stop HIV becoming worse ... those are too expensive and even if I sold my house we could not have medicines for more than two years.*

Twelve carers spoke about their inability to afford allopathic treatment for their family member living with HIV/AIDS. Their accounts reflect the difficulties that they experienced when they were unable to provide their loved ones with basic medicines to relieve their symptoms. The accounts of Sajini, Savithri, Bindu and Mary expressed similar themes. Sajini recalled a time when her husband was prescribed a medicine for his cough. She said:

> *I walked to the medical shop to the nearest town because I wanted to save money for the medicine. When I reached there I found that each medicine was 56 rupees. He was supposed to take 4 a day for 10 days ... I only had enough money to buy 2 medicines ... I sold my gold chain and bought the medicine ... now I have nothing left to sell for medicines.*

Bindu recalled a similar experience. She said:

> *My husband was told to take medicine for his cough, but we could not afford that expensive medicine. In the night when he coughs he sounds as though he is unable to breathe. I cannot sleep at night and spend the night crying in my pillow. If only I could buy him this medicine, then he will not have to suffer ... the ayurvedic medicine which he takes now, is not helping him ... I feel so helpless.*

In comparison to the carers in Kerala, the carers in Scotland had adequate medical support as well as some help from social services and voluntary organisations. Julia and Trisha said that they were able to manage with little outside assistance, often describing a sense of duty towards their family member living with HIV/AIDS. Julia said, *"I would do it for my son irrespective of what support I get from them"*.

Trisha too felt that it was her duty to care for her daughter irrespective of the support she did or did not receive. She said:

> *We have received support from the social services and a voluntary organisation that have been most helpful, but I am prepared to do almost anything to be there for my daughter and her child.*

Three carers in Scotland (Kate, Julia and Trisha) who were parental carers identified the following areas of support that could be improved: respite, information provision, and general support services. They highlighted the need for improved psychosocial services that can be accessed without waiting for long periods. Another area that they emphasised was the improvement in the provision of welfare and benefits services. Kate spoke about completing huge forms to get a simple benefit. She said:

> *It's really ridiculous that I have to spend so much time and effort to manage to get something that should come to me quite simply ... I don't think that they* [Benefit Agency] *appreciate the kind of time that goes into these things.*

Finally four of the five carers from Scotland spoke about a lack of recognition of their needs as carers of persons living with HIV/AIDS. Trisha's account clearly reflects this issue. She said:

> *I often feel that our services and dedication are not really appreciated for what they are. The Government saves millions of pounds because*

> *of people like me who provide care and support to our loved ones, without much hope for any reward.*

Although the carers in Scotland were not faced with the extreme hardship experienced by the carers in Kerala, they still had to cope with bureaucracy and inadequacies in the support available to them and the HIV/AIDS-affected person. In both settings, the carers often found themselves acting as advocates for the HIV/AIDS-affected family member, who might be too ill or demoralised to seek help directly. The need for additional supports designed particularly for the carers is evident in both settings.

Summary

The two previous themes have reflected the carers' experiences with formal and informal support. The differences between Kerala and Scotland are particularly striking in this area, due to the tremendous differences between the two countries in terms of resources and general understanding regarding HIV/AIDS. The plight of the carers in Kerala is particularly evident. These carers are at the greatest need for support, given their poverty and isolation, yet they find very little in the way of either informal or formal support. The insidious effects of stigmatisation and ignorance regarding HIV/AIDS, together with the lack of basic services and medical infrastructure, leave these carers with nowhere to turn at a time of very great need.

The carers in Scotland are afforded a much higher level of counselling support together with a well-developed system for delivery of medical care and protection of patient rights, yet they still experience difficulties in obtaining needed services for the HIV-affected person, and they find few resources directed towards them in their role as carers. These findings point to a great need for recognition and support of family carers, which will be further highlighted in the discussion chapter.

Towards a Synthesis of the Six Themes

The previous sections have presented the six themes that emerged from the interviews with carers in Kerala and Scotland, highlighting the aspects of the experience of caring that were important for the carers. These themes show the many facets of the experience of caring for a family member with HIV/AIDS, reflecting the complexity of this situation and the many difficulties encountered by the carers in their day-to-day existence.

Despite this complexity, however, a process of reflection suggests some unifying concepts that may help to capture the essence of the experience of caring. During the process of fieldwork and later during data analysis, the concepts of struggle, commitment, and resilience seemed to resonate strongly through the stories of the carers. The notion of struggle reflects the many obstacles and heartbreaks that the carers encounter in dealing with experiences such as physical exhaustion, anxiety and loss, economic crises, complex family concerns, social isolation, and rejection. Commitment reflects the unquestioning bonds of duty and affection that led the carers to undertake and continue to bear the daily burdens demanded by caring. And finally, the concept of resilience reflects the strength and resourcefulness of many of these carers, who found a way to go on when it seemed that they had lost everything. These three unifying concepts are further explored and elucidated in Chapter 8, and a model reflecting the concepts is proposed. The model endeavours to explain family caregiving in the context of HIV/AIDS.

To further illustrate the experience of caring in the two settings, three case vignettes will be presented in the next section. These vignettes present three carers' stories as integrated narratives, to better illustrate the combined influences of the experiences described in the themes presented above.

Case Vignettes

The previous section has presented an outline of the themes that emerged from the data, together with some examples of the various issues and concerns raised by the carers. This section provides three case vignettes that illustrate these issues in more detail. Two of the vignettes illustrate the circumstances faced by the carers in Kerala; the third vignette illustrates the circumstances in Scotland.

Sheena, a 28 year old housewife, lived with her husband and a child in a small town in Kerala. She was educated to a degree level, and she spoke articulately about her life and the circumstances in which she found herself. Her husband ran a small bakery which was the main source of their livelihood; he had to close down the bakery since his diagnosis. Her story began when she was admitted into a large private hospital for the delivery of her child:

> *I was admitted into a private hospital for my delivery and during my labour I needed blood. My husband volunteered and was asked to test before donating. This was the turning point. The test showed my husband positive for HIV. They wrote this test result on top of the medical case paper.* [Up until then] *The staffs were looking after me well, but after they tested his blood for HIV, their behaviour changed. They did not touch me after that, stitching was yet to be done and there was no further treatment and I was discharged from that hospital.*
>
> *I was rushed in an ambulance to the Medical College Hospital (Government run) situated in another town. On reaching there, I was put into a cell and was quarantined. Nobody would come near me, no medication was given and nobody even talked to me as to what I was having or why I am being treated this way. They separated me from others and talked about us in a hushed tone. I could not understand why their behaviour had become so cold and pathetic.*
>
> *A few nurses in the hospital told me that HIV spread through air, so sneezing or spitting may cause infection to other patients and asked us not to speak or mix with others around. They put food in a plate and pushed it through the door. They did not test me, but assumed I was also positive. I asked the doctor who came around what was happening to me, but he ignored and advised the nursing staff that I should be kept separately.*
>
> *Somehow my husband managed to get me out of that place. By this time everyone in my family and the village came to know of my husband's positive status and word was sent that we were no longer welcome back into our little house. So we had to flee to Bombay, where we stayed with a friend and saw a doctor who did the stitching for me almost 2 weeks after the delivery.*

This vignette shows not only the indifference on the part of the medical staff towards the person with HIV and their carer, but a lack of accurate knowledge and belief in stereotypes that exist in relation to HIV/AIDS. In many cases carers have to face the unexpected turn of events if they are attending a private hospital for treatment. Once diagnosed for HIV these person are transferred to government hospitals where the conditions and the quality of care are often very poor. A doctor in a private AIDS clinic where another interview was conducted confirmed this:

> *In private hospitals the news of the HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to a government hospital. This adds to the misery of the carers, as there is little chance of their identity being concealed and subsequent ostracism from the staff and other patients is guaranteed.*

He went on to say, *"In private hospital the doctors are not bound by any rules to give treatment to positive persons or their carers. They think the government hospital should take up this responsibility".*

After the initial shock of HIV diagnosis, Sheena continued to experience subsequent shocks as the implications of the diagnosis spread through the community. One of the most difficult experiences for Sheena and her husband was the loss of their livelihood:

> *My husband was running a small bakery, this kept our family going. However the news of my husband's HIV diagnosis spread like wildfire. People started telling that we can not keep the bakery open anymore; HIV can spread through contact with the bakery product. One day, a local man came into the bakery and started shouting at my husband to close down the bakery. People stopped buying things from us. So we were forced to close down our means of livelihood.*

The loss of the bakery business led to financial hardship, which they could not alleviate by finding work:

> *... it has been very difficult, no jobs either for me or my husband for the past 2 years. Not even some manual labour. We asked a few of our friends to do manual jobs in their farms, but they showed no interest. Now I just wish I could get some jobs. I have not asked anyone for any money nor has anyone given me anything knowing my current situation. Feel very lost in this world. My husband and I have helped many of our friends when we could, now nobody we can turn to.*

Thus the advent of HIV/AIDS in this family led to a multitude of other problems. Although the family had previously enjoyed a modest level of financial comfort, they were now facing poverty in addition to the isolation and worry brought about by

HIV/AIDS. And in this case, the support from family of origin, which might be forthcoming in other crises, was also lost.

Despite previous good relationships with their respective families, Sheena and her husband found that very little support was forthcoming from either family. Family members were subjected to ostracism from the larger community, and reacted by distancing themselves from Sheena and her husband. She said:

> *... there were several problems following our return to our house. There were a lot of arguments in the family. People stopped buying milk from my parental home ... People stopped coming to their house, no one talks to them. This led to increased tension in my parental house. Finally my parents sent word to me to say that we were not welcome in my family home. For the past 3 years I have not gone there. I think my family is afraid that they would be isolated and ostracised by the society due to my condition. So they severed all ties with me; they don't visit me, nor do I. I have thought several times of visiting my parents; but I know that would lead to further tensions as my sister is about to get married and that can lead to disruption; neighbours would spread bad news.*

These incidents highlight the aspects of struggle faced by many carers in Kerala. The general lack of understanding regarding HIV/AIDS leads to fear and rejection in the larger community, which in turn leads to emotional and financial hardship for the HIV/AIDS-affected person and the carers. As Sheena so poignantly put it, "*...we need a community to live in; and support from each other, and family support is very vital, but my family gives importance to the society: what the society think and say*".

Despite hardships such as these, many carers continued to show a high level of commitment to caring for the HIV/AIDS-affected family member. Sheena's case also illustrates this aspect of caring. Although she was rejected and ostracised by her family of origin and by the people in the village where she and her husband once lived, Sheena has continued to provide loving support and care. When asked how she came to the decision to become a carer for her husband, she commented:

> *It came as natural; thought about it and made a conscious decision to look after my husband, with love and happiness to the best of my ability. If it comes to a stage where we can't cope, we have decided that we would not be a burden to anybody ... we would end our lives* ... [she then showed me a sachet of poison which she carries with her].

Among the most challenging issues faced by Sheena and her husband are their concerns about the welfare of their daughter. Sheena has shown relatively little concern about contracting HIV herself; however, she continues to worry that she may inadvertently pass the disease to her child. She also worries about providing for the child if she and her husband should both die, and about finding a way to tell her about the HIV diagnosis.

Like most of the carers in Kerala, Sheena has found very few resources that she can rely upon for medical, social, or financial support. Her husband has received no medication because they cannot afford it. Sheena herself has not even been tested for HIV. They have received no education regarding HIV/AIDS beyond a few newspaper articles and pamphlets, which have helped them to understand how the disease is transmitted. With no resources in place for counselling or financial support, and with the lack of any support from informal sources such as family members, Sheena and her husband have had to find their own ways to cope with the many struggles created by the advent of HIV/AIDS in their lives.

Although they have lost much, Sheena and her husband continue to have a strong relationship:

> *We share feelings, emotion, pain, joy with each other. That is the only source of comfort... [We make] decisions jointly, we never had a disagreement or difference of opinion; we also share our feelings, wants and make decisions together. We feel stronger together as we have nobody now to really relate to.*

Sheena's story illustrates the hardships faced by carers in Kerala, as well as the high level of commitment shown by many of the carers. It also reflects the acceptance and ultimate resilience of many carers, who face multiple losses, yet find a way to go on.

The account of Gangabai illustrates the desperation experienced by some carers, who literally lose everything. Gangabai was in her early forties when she was interviewed. She came from an economically poor background. Her story illustrates the discrimination, isolation and the pain she experienced in the face of this epidemic.

Prior to the advent of HIV/AIDS in her life, she was a happily married woman, living a simple life with her husband and son. Her husband worked as cleaner/driver and her child was attending school. They had family and friends, until her husband was diagnosed:

> *I only discovered that my husband had AIDS when our neighbours came and harassed us and threatened us with dire consequences if we did not leave our home and neighbourhood. He was very unwell and had been visiting the hospital along with his brother. He was having chronic diarrhoea, fever and had severe cough; he was losing weight. The doctors did a blood test. They told his brother that he had got AIDS and discharged him asking him to take him to the medical college hospital in Calicut* (i.e. the next town). *He was admitted to the hospital where he was put in a cell; few days later he ran away from the hospital and came back to our house in the night. Although, unknown to me, by this time people in our neighbourhood had discovered from someone that he had AIDS. When they found him home, they raised an alarm. They literally managed to chase us out of our own home and alerted the police. We had no place to go, and my husband's condition was very poor. The police took us to this hospice and admitted him in here. I had nowhere to turn, so I took refuge with my sister. She is very poor, but she gave my child and me shelter.*

The only resource that Gangabai's husband was able to find was a hospice run by Christian missionaries. *"This is a hospice for the destitute, and the care is very limited. They do not have much resource, [but] the sisters* (nuns) *are very supportive; I am happy at least they took him in".*

As with Sheena's case, the diagnosis became public knowledge and led to severe financial hardships for Gangabai and her child:

> *When I began enquiring about any domestic jobs, people started saying she has HIV, her husband is dying of AIDS, don't give her a job; this was major problem in getting a job. I worked as a domestic with a rich family; they came to know that my husband has AIDS and they asked me not to come from then on.*

Gangabai and her husband tried to find support from family members, but found that they were no longer welcome. They experienced reactions similar to those described by Sheena:

> *...since diagnosis, my family has disowned me, my brothers, their wives and children used to visit us. Now nobody comes to see us. Nobody from my husband's family either. Once they came to visit him; they stood at a distance and saw him lying on the bed and went away.*

At the time of the interview, Gangabai's husband was severely ill with AIDS and staying in a hospice. Although she was beset by worries and often exhausted, Gangabai continued to provide much of the care for her husband:

> *I come every morning and help with nursing, toileting, washing, feeding etc until evening when I go home. This affects me physically, I am exhausted at times, can't get sleep with worries about how I would manage everything. But I keep going as I feel I have a duty to take care of my husband.*

Gangabai's unquestioning commitment to her husband echoes that described by Sheena. In Gangabai's case, her husband had deceived her about his condition for some time, and she only discovered his HIV status after he had become ill:

> *I noticed him losing weight and falling sick, but he said he might have TB. One day he was found lying on the railway lines wanting to commit suicide. He was found by the guards before the train came; he was in a terrible state. People told me about this later. Even after being admitted here, I feel sad that he did not tell me, but I have forgiven him.*

She continued to support him and care for him, despite his lack of honesty with her. As she put it,

> *My husband looked after me so well, he would do all he can if I became sick. Now I have to look after him... I have made a conscious decision to visit my husband and be there for him all the time. I use part of the money the doctor gives me for buying milk for him.*

At the time of the interview, Gangabai and her son were destitute, living in a hut, with no one to turn to but a local physician who gave her money to help buy food. Gangabai commented on her desperate situation as follows:

> *It is such a struggle; I have to visit my husband in the hospice, provide for my child and keep my head high. It is too much to cope. I had no money to buy food for my child, so he has not eaten ...* [she breaks down in tears] ... *I am hoping the doctor would give me some money today.*

Gangabai's account illustrates the devastating impact that social ostracism and ignorance has on families affected by HIV/AIDS. In her case, the lack of privacy in her community led to widespread disclosure of her husband's medical status, and she had no hope of shielding herself and her family from social rejection and ostracism, which extended even to her own family of origin and that of her husband. As a result, she has been unable to find work to support the family. She recalled:

> *People in the community somehow came to know even before me, about my husband's diagnosis. They spread the news that we have AIDS. Now they don't talk to me. People try to keep their children away from me and my child in case we meet in the streets. So I feel very isolated and lonely; nowhere to go. My husband's family once blamed me for him getting AIDS. I don't know why; they don't talk to me; so I don't know what they think now... I tried to find a job, but nobody wants to employ me as they fear I would also have HIV.*

This case illustrates the ways that poverty and ignorance add to the plight of many carers, particularly those in developing countries. Again, the concepts of struggle and commitment are evident in her story; however, Gangabai's desperate situation has taken its toll, and she seems close to despair.

The case of Ann, a carer from Scotland, illustrates the similarities and differences experienced by carers in a more developed context. Her story of caring began in the first year of her marriage. She and her husband were on holiday and her husband took a chest infection and his health rapidly deteriorated. Tests revealed that he had advanced HIV. Subsequently it was discovered that she too was HIV positive. Ann describes her initial reaction:

> *I was terribly shocked and felt pretty crap... We did not know how long he had to live and that really upset me... I think the thing I felt most was really angry, and really sad. But I remember feeling really angry that he was a good guy; that he hadn't done anything wrong, you know, and just by bad luck had become positive. He was really a handsome and clever and I just, I remember feeling angry, because I remember feeling that God, there are so many horrible people in the*

> *world, that don't suffer from AIDS, but do awful things and live to ripe old age. And this really wonderful man isn't going to.*

Like many of the carers in this study, Ann undertook the responsibility of caring for her husband as a matter of course. She commented on the decision as follows:

> *Although I tested positive too, my thoughts and energies were all focused on my husband. His health was rather poorly, whereas I was free of any symptoms at the time. I wanted to be as caring and attentive to his needs as I possibly could be. Caring for my husband and being positive myself have put my own health and mortality in to sharp focus ... I remember feeling ... a kind of ... not blasé, but didn't really matter about me because I felt totally committed to being there for him and caring for him.*

Ann and her husband had financial resources that allowed them to continue a relatively comfortable lifestyle, and they received public assistance when Ann's husband was no longer able to work. They also received emotional support from family of origin.

Despite these advantages, Ann still experienced the isolation and exhaustion that is common for carers in this circumstance. Making the decision to tell others about their HIV status was very difficult:

> *At that stage we were very wary of telling anyone about our diagnosis ...... well my husband did not want anybody to know what was wrong with him for a long time.... and he didn't tell any of his friends until really when he got very unwell. I think because we did not know anyone who was positive, as far as we knew. And then we kind of, you know if you tell somebody you're positive there is always.... they always think even if they don't ask they always wonder where you contracted the virus, I guess. And we didn't particularly want to talk about that.*

She and her husband also experienced stigmatization in relation to their HIV status, which extended even to trained medical personnel:

> *When he became really unwell it became quite difficult for me to lift him and these two nurses came to help in the evening to help to put him to bed. ...These nurses came and they put two pairs of gloves on to transfer him from the chair to his wheelchair. ... And then they asked me for a yellow bag to put them in. Because in hospitals infected rubbish goes into yellow bags and ordinary rubbish goes into black bin bags. And the bin bags with the yellow bags get incinerated.*

> *So they wanted me to have these yellow bags in the house and I said, "I don't have any of these, because I am in the house". And they said well you should have them. And I said I don't have an incinerator. But they honestly thought I should and that I should get a special lift to take these bags for incineration.*

Although the higher level of general awareness regarding HIV/AIDS and the greater availability of services are evident, nonetheless Ann and her husband faced some reactions that were similar to those faced by the carers in Kerala. Both of them were initially very reluctant to disclose their HIV status to family members and friends, for fear that they would be blamed and rejected. As Ann noted:

> *People imagine HIV positive people to be thin, people who look like skeletons, living on benefits, not able to do anything. The kind of images you'll see on TV. So there is that, but there is also this assumption.... partly because of all the stories in the press, that all people who are positive are gay men or prostitutes and drug takers.*

Ann's story contrasts greatly with those of many carers in Kerala. She and her husband continued to enjoy relative stability and comfort, despite the advent of HIV/AIDS in their lives. Even so, Ann experienced the fear of ostracism and the physical and emotional burdens of being a carer, which were intensified by the fact that she was HIV positive herself:

> *I did quite a lot for him initially, but when he became really unwell, we had people come round to the house to help...nurses etc because I got very exhausted. I was not concerned about my own health, but I just did not have the strength to do everything myself. Over the past few years I have had to deal with a lot in terms of my own health. I have been on combination therapy which has changed my life. I might have been dead or certainly very frail.*

This vignette highlights some of the differences that a well-developed medical care system and a greater level of general education can make for family carers dealing with HIV/AIDS in a family member. It also points out the impact of combination therapy, which has made a great difference for HIV-affected individuals in developed countries where it is available.

Like many carers, Ann has developed a sense of acceptance and understanding concerning her circumstances. Her remarks suggest her underlying resilience as she deals with the struggles of caring for her husband and living with HIV/AIDS:

> *When something really big happens in your life you start feeling and caring for people in a different way. But it only really happens if you've got people to support you and to remind you. I have had a lot of support from my family and some friends. It makes me feel I can be quite strong and deal with things.*

Although the family carers in Scotland still experienced a number of burdens associated with providing care, they were not faced with the degree of poverty, isolation, and hopelessness experienced by the carers in Kerala. While the themes of struggle, commitment, and resilience still run through their stories, they occur against a different backdrop, where greater resources and hope are evident.

Conclusion

This chapter explored the varied experiences of 23 family carers from Kerala and 5 from Scotland that emerged from their interviews. The interviews produced rich qualitative data that were analyzed using the qualitative methods described in Chapter 4. This led to the emergence of six distinctive themes.

The first theme looked at the advent of HIV/AIDS in the life of a family member. It described the circumstances under which the carer discovered that her/his son, daughter, husband, partner, or sibling had been given an HIV/AIDS diagnosis. For the vast majority of the carers the deteriorating health of their family member heralded the advent of HIV/AIDS in their lives. This theme goes on to explore the broad range of initial reactions that included shock, panic and confusion, fear of stigma, and fear of losing the loved one. The carers' stories reveal many unique circumstances related to the advent of HIV/AIDS, due to its stigmatising nature. They highlight the fact that many of them lacked a basic awareness about HIV/AIDS at the time of diagnosis, which often persisted and was still evident at the time of the interviews. What is demonstrated in this theme is the love and sense of duty and commitment to provide care for their loved-one. These aspects, together, portray the experiences of the carers in both contexts as they encountered a life-changing event—the advent of HIV/AIDS in their lives.

The next theme explored the experience of caring for a HIV-positive family member in the midst of poverty, appalling ignorance, and overarching stigma for the carers in Kerala; and the relative poverty, limited information, and fear of stigma for the carers in Scotland. The experiences of carers in both contexts highlight the physical burdens of caring, the exhaustion and sheer tiredness that their role as carers involved. It also explored the emotional reactions of worry, anxiety, panic, confusion, stress, anger, and a sense of betrayal that were experienced by carers in both contexts.

Additionally, this theme encompasses the difficult social climate for those dealing with HIV/AIDS, which is one of the most crucial experiences of the family carers in both contexts. These experiences echo the experiences of those infected and affected by HIV/AIDS all over the world. The accounts of the carers in Kerala were particularly hard-hitting in this regard, because they told of the appalling levels of discrimination, stigma, rejection, ignorance, and prejudice that prevail in the third decade of the epidemic. They were ironic because Kerala, (as discussed in Chapter 3) though regarded as a paradigm of development, has created an environment where persons living with HIV/AIDS and their families are subjected to severe discrimination and inhumane treatment. The accounts of the carers in Scotland also highlight actual and perceived experiences of stigma and discrimination, which are less intense than those experienced in Kerala, but nonetheless represent a source of worry and distress for the carers. Against this social background, many of the carers faced the stark realities of providing care amidst poverty, hardships, and lack of resources.

The third theme examines the aspect of family dynamics while caring for a family member living with HIV/AIDS. It looks at how the advent of HIV/AIDS in the lives of carers impinges on very personal aspects of the carers' lives, that is, patterns of interaction and communication, issues of sex and reproduction, and issues related to children. The accounts of carers from both contexts revealed that these issues could have a profound impact on their personal being and on the fabric of the family itself. With its sexual and immoral overtones, as well as its potential to take the life of the family breadwinner, the HIV/AIDS epidemic poses a threat to family life. Even without this threat, the presence of HIV/AIDS in the family alters family relationships and roles and creates confusion and uncertainty for family members.

The theme that followed presented the unique theme of being HIV-positive and caring for a family member living with HIV/AIDS. Two carers in Scotland spoke about the complex dimensions of the affective and social aspects of being HIV-positive and caring for a loved one who was also HIV-positive. Rather poignantly the accounts of some carers in Kerala portrayed the complex dimensions of their fears of being ostracised or recriminated, their superstitions and lack of resources that kept them from being tested or even wanting to be tested.

The fifth and sixth themes discussed the social support networks and formal support services received by the carers in both the research contexts. Distinct differences were highlighted by the carers in Kerala and Scotland. The predicament of the carers in Kerala was particularly marked by the absence of the much needed informal social or formal statutory support. Nearly all the carers were left to fend for themselves without any support from their extended family or friends or from any organized agency. In addition, they experienced lack of confidentiality, appalling ignorance, prejudice, and apathy on the part of medical professionals. Their stories poignantly demonstrate their critical need for informal or formal support in the face of poverty, stigma and isolation.

Through these six major themes, the phenomenon of family caring has emerged as a process that encompasses three key concepts of struggle, commitment, and resilience. These three concepts capture the essence and the commonalities of the caring experience, and they will (as mentioned earlier in this chapter) be examined further in Chapter 8.

Finally, in order to illustrate the themes in greater detail, the experiences of three carers were provided in the form of case vignettes. As Marshall and Rossman (1989) suggest, case vignettes add an important dimension to qualitative studies such as this one. Marshall and Rossman note that people's experiences and stories have a strong appeal for readers, because of their subject matter and because of the narrative form in which they are written. The case vignettes included in this chapter present coherent pictures of individual participants, throwing light on the essence that was gleaned from the interviews and the transcripts. They touch upon the core ideas that are central to the carer's experiences of living with a HIV positive family member and offer a vicarious experience (Stake 1995) of the complexities of their lives.

It is worth noting that although the study made the socio-cultural differences between the carers in Kerala and Scotland visible, there was no evidence to indicate the existence of polarisation of views either between respondents within a context, or between the two contexts. This is not to say that the intensity of the experience did not vary considerably. The experience of caring for a family member living with HIV/AIDS was similar, irrespective of the geographical contexts or contexts of development in which they lived. This was perhaps because caring for a loved-one involves visceral issues of love, emotions, sense of duty to one's family and loved-ones, and caring for their ill family member. These visceral ties of love and duty seemed to overrule whatever fears the carer may have had for their own safety or reputation in a context of social stigma related to HIV/AIDS.

In closing, the very real sacrifices made by the carers in both contexts bears testimony to their struggle, commitment, and resilience in the face of many adversities. It stands out as one of the most touching facets of the phenomenon of family caring for a person living with HIV/AIDS. Without their sacrifices, many HIV-positive persons, who they were caring for would have been bereft of care and consolation. Yet, surprisingly, very little attention or recognition is given to these carers themselves, who give so much and receive so little in the way of support.

The next chapter presents the quantitative findings that emerged from the study, focusing on the coping strategies and the mental health of the family carers. That chapter, in contrast to the present one, will focus on group comparisons and statistical analyses, in order to convey another dimension of the experience of the family carers.

CHAPTER 7: QUANTITATIVE FINDINGS: COPING AND MENTAL HEALTH

Introduction

The previous chapter presented the qualitative findings that emerged in relation to experiences of caring for a family member living with HIV/AIDS. This chapter looks at the quantitative findings that emerged in relation to the ways of coping and mental health of the family carers of family members with HIV/AIDS. Additionally, it explores quantitative data concerning the coping strategies used by carers, and the mental health problems experienced by them. The material in this chapter is exploratory because of limits to sample size; however, it suggests directions for further research.

As discussed in the chapter on methodology, two research tools were utilized to study the coping strategies and mental health of the carers in both the settings. Coping strategies were studied through the use of the revised Ways of Coping scale (WOC; Folkman & Lazarus, 1985) that was modified by the researcher to consist of 85 items, each describing a particular behaviour that an individual could use to cope with a stressful experience. The respondent answers "Yes" if he or she has engaged in that behaviour, and "No" if he or she has not engaged in that particular behaviour. For scoring purposes, each "Yes" response is given a score of 1, and each "No" response is given a score of 0.

Mental Health was studied using the Self Reporting Questionnaire (SRQ) (World Health Organisation, 1994), which consists of 20 items that describe various non-psychiatric mental health symptoms. The Self Reporting Questionnaire was developed as a screening instrument to assess mental health symptoms in various populations, and as such, it provides an indicator of overall distress but does not diagnose specific disorders.

Coping Strategies in Kerala and Scotland

The individual items of the WOC comprise 9 scales, each of which measures a particular strategy for coping with stress. The scales vary in length from 2 items (Self Blame) to 14 items (Escape/Avoidance). The score on each scale is the sum of the "Yes" responses to the items that make up the scale. The meaning/content of each of the scales is described below.

Content of the WOC Scales

Caring for a family member living with HIV/AIDS is a major, demanding life event that could lead to feelings of intense confusion and distress. Studies in the area of stress identify a variety of coping strategies, each of which can vary in the degree to which it is helpful in coping with a particular stressful situation. Each of the strategies included in the WOC is described below.

Problem Focused Coping

Problem-focused coping is one of the methods whereby a person confronts the problem that needs to be restructured or ameliorated, such that it reduces distress (Folkman & Lazarus, 1985). In problem-focused coping, persons try to short-circuit negative emotions by taking some action to modify, avoid, or minimize the threatening situation. They change their behaviour to deal with stressful situations. This 12-item scale suggests a relatively direct approach toward dealing with stress, by doing things that help eliminate the problem. In the context of caring for a family member with HIV/AIDS, problem focused coping might include activities such as seeking medication, seeking financial aid to pay for care, and similar activities.

Positive Reappraisal

This strategy describes efforts to create positive meaning by focusing on personal growth. It is a cognitive strategy in which the person deals with stress by trying to think about the situation in positive terms. Focusing on the positive is the effort to approach the stress with a constructive attitude. This strategy includes finding new faith, rediscovering what is important in life, and changing or growing as a person in a good way (Dunkel-Schetter et. al, 1992). In the context of caring for a family member with HIV/AIDS, positive reappraisal might involve focusing on the positive qualities of the relationship with the ill family member, focusing on signs that the situation is improving, and similar activities. The scale includes 12 items.

Accepting Responsibility

This strategy involves dealing with stress by thinking about one's duties and obligations and accepting them and recognising one's role in solving a problem. In this strategy, the individual acknowledges one's own role in the problem with a concomitant theme of trying to put things right. In the context of caring for a family member with HIV/AIDS, this might involve thinking about one's responsibility as a family member. This scale includes 5 items.

Seeking Social Support

This strategy involves the effort to establish and use interactions with persons who could provide information, tangible, or emotional support. It includes seeking help and comfort from others, finding out more about the disease, talking to someone about how the person is feeling, getting professional help, and looking for sympathy and understanding. Support can come from family members, friends, religious advisors, and variety of other sources, depending on the circumstances. In the context of caring for a family member with HIV/AIDS, this might include formal support groups for people in similar circumstances, as well as more informal contacts. This scale includes 10 items.

Self Controlling

This strategy describes efforts to regulate one's feelings and actions. This scale measures a tendency to avoid impulsive behaviour and to think through various approaches to handling a stressful situation. In the context of caring for a family member with HIV/AIDS, this might involve trying to avoid panic about the situation and thinking about one's options. This scale includes 6 items.

Tension Reduction

This strategy involves dealing directly with one's emotional reactions to the stressful situation. Stress reduction techniques include muscle relaxation, guided imagery, distraction, meditation, writing a journal, and biofeedback. Activities such as exercise, meditation, prayer, and other ways of promoting relaxation and calming would be included here. This scale includes 14 items.

Self Blame

Self-blame arises out of feelings of helplessness and powerlessness. This strategy involves self-criticism and other negative thoughts about one's own role in the problem. When individuals are unable to feel in control of their lives, or are unable to maintain some level of predictability or a sense of influencing the outcome of their lives they are most likely to blame themselves. In the context of caring for a family member with HIV/AIDS, this might involve criticizing oneself for failure to achieve certain goals. This brief scale includes 2 items.

Distancing/Detachment

This strategy involves dealing with the problem by trying not to experience distressing feelings. This describes cognitive efforts to detach oneself and to minimize the significance of the situation. In the context of caring for a family member with HIV/AIDS, this might involve trying not to feel too close to the ill family member or avoiding discussions about the family's situation. This scale includes 10 items.

Escape/Avoidance

This strategy involves dealing with emotionally distressing situations by trying to escape from them. The items describe wishful thinking and behavioural efforts to escape or avoid the problem. It can include physical avoidance of the situation, as well as distorting one's consciousness by using drugs. This scale includes 14 items.

This section has helped to explain the meaning of each of the nine WOC scales by describing their content and explaining how the coping strategies included in the scale might be relevant in a context of coping with caring for a family member with HIV/AIDS. In the next section, the scores on these scales will be compared for Kerala and Scotland.

WOC Scores in Kerala and Scotland

Tables 13 and 14 present the median and range of scores for each of the nine scales earned by the respondents in Kerala and Scotland. The median scores reflect the importance of each coping strategy in each setting, because a higher median score indicates that more of the participants reported using that coping strategy. Median and range scores were reported rather than means and standard deviations because of the small sample size. Mean scores in such a small sample might have been unduly influenced by one or two aberrant scores; whereas median scores are not affected by aberrant scores.

Table 13
Median and Range of Scores for Coping Scales in Kerala (n = 23)

Scale	Median	Range
Escape/Avoidance	7	5 to 10
Seeking Social Support	5	1 to 8
Positive Reappraisal	5	2 to 7
Tension Reduction	4	1 to 8
Problem Focused Coping	3	1 to 8
Distancing/Detachment	3	2 to 6
Self Controlling	2	1 to 4
Accepting Responsibility	2	0 to 4
Self Blame	1	0 to 2

As Table 13 indicates, Escape/Avoidance emerged as the most frequently endorsed coping strategy used by the Kerala sample. Seeking Social Support and Positive

Reappraisal were tied as the second most important strategies followed by Tension Reduction. Problem Focused Coping, the only strategy that directly attacks the source of the stress, was ranked fifth.

Table 14
Median and Range Scores for Coping Scales in Scotland (n = 5)

Scale	Median	Range
Positive Reappraisal	9	6 to 11
Escape/Avoidance	7	6 to 9
Seeking Social Support	7	6 to 8
Distancing/Detachment	6	4 to 7
Problem Focused Coping	6	3 to 9
Tension Reduction	6	3 to 7
Self Controlling	5	4 to 6
Accepting Responsibility	3	0 to 4
Self Blame	0	0 to 0

As Table 14 indicates, the most commonly chosen coping strategy for the Scotland sample was Positive Reappraisal, followed by Escape/Avoidance and Seeking Social support. Problem Focused Coping also earned a relatively low score in this sample.

In both the Kerala and Scotland groups, strategies that sought to avoid the negative feelings associated with caring for a family member with HIV/AIDS seemed to be predominant. This may reflect the fact that this particular circumstance engenders many difficult emotions, and may also reflect the difficulty of coping more directly with the problem in either setting.

The differences in the median scores of the scales in the different settings suggests that the Kerala and Scotland groups were using somewhat different approaches to coping with their circumstances. In the next section, the scores for the two samples will be compared scale by scale.

Comparison of Ways of Coping Scores

To determine whether individuals in the two settings utilized significantly different coping strategies, the Ways of Coping scores for the Kerala and Scotland samples were compared using the Mann-Whitney U Test. This test was chosen because of the small size of the Scotland sample, which did not allow the researcher to meet the assumptions necessary for a parametric test such as the t-test. The Mann-Whitney U Test results for each of the nine Ways of Coping scales will be presented in the Table 15. It should be noted that the size of the Scotland sample used in these analyses was very small (N=5), and therefore the results should be interpreted with some caution, since the scores obtained from the Scotland sample may not be representative of the population as a whole.

Table 15
Mann-Whitney U Tests for Ways of Coping Scale

Scale	Mann-Whitney U	Significance (two-tailed)
Problem Focused Coping	20.00	.022
Positive Reappraisal	6.00	.002
Accepting Responsibility	51.00	.684
Seeking Social Support	9.50	.003
Self Controlling	1.50	.001
Tension Reduction	48.00	.563
Self Blame	27.50	.043
Distancing/Detachment	16.50	.012
Escape/Avoidance	44.50	.422

It can be seen from Table 15 that the Kerala and Scotland samples differed significantly on six of the nine Ways of Coping measures. Respondents from Scotland earned significantly higher scores for Problem Focused Coping, Positive Reappraisal, Seeking Social Support, Self Controlling, and Distancing/Detachment. Respondents from Kerala earned significantly higher scores for Self Blame. Although these data are exploratory, they do suggest that the respondents in the two setting used distinctly different coping strategies to handle the stresses of caring for a family member with HIV. Each of these findings will now be discussed separately.

Problem Focused Coping

The respondents in the Scotland sample (median score 6.00) earned significantly higher scores on the Problem Focused Coping scale than did the respondents in the Kerala sample (median score 3.00). This suggests that the individuals in the Scotland sample were more likely to utilize direct strategies to deal with stress, by taking steps to deal directly with the source of stress. It is possible that the Scotland respondents used this strategy more because they actually had more steps that they could take, for example, access to social services, more practical assistance to apply for, etc. Whereas the respondents in Kerala did not have such services available to them.

Positive Reappraisal

The respondents in Scotland (median score 9.00) earned significantly higher scores on the Positive Reappraisal scale than did the respondents in Kerala (median score 5.00). This suggests that the individuals in Scotland were more likely to use cognitive strategies that involved reframing the problem in some sort of positive light. They focused on personal growth or acceptance that they derived from the experience of caring for a loved one with HIV/AIDS, as opposed to focusing on the loss and pain that they were experiencing. The difference between the respondents in the two settings may also suggest that the carers in the Kerala sample were feeling overwhelmed by the burdens they were experiencing. Given their lack of resources and constant level of stress, they may have been unable to think positively about their experiences.

Accepting Responsibility

The Kerala and Scotland samples did not differ significantly on this scale. They thus appeared equally likely to utilize this strategy in coping with the stress they were experiencing. This scale might not be particularly relevant for the respondents in this study, since it focuses on taking responsibility for one's own problems. The respondents in this study may have felt that their circumstances were completely out of their control, since their own behaviour could not directly change the likelihood of their loved one developing HIV or AIDS. Thus, taking responsibility would not occur to them as a coping strategy, except perhaps to acknowledge their responsibility as sources of family support.

Seeking Social Support

The scores on this scale were also significantly higher for the respondents in Scotland (median score 7.00) than for those in Kerala (median score 5.00). The individuals in Scotland were thus more likely to seek help and solace from others, either through informal contacts with friends or through participation in more formalized support services, such as support groups. It is possible that the social circumstances of the respondents in Kerala may have influenced this result. These individuals were much more likely to be stigmatised because of fear and misunderstanding about HIV and AIDS, and thus they may have been reluctant to confide in friends or even in relatives. Also, formal support services, such as support groups, would be lacking for the individuals in Kerala. Thus, even if they wanted to seek social support, this avenue may not have been open to them.

Self-Controlling

This scale seems to measure a tendency to avoid impulsive behaviour and to think through various approaches to handling a stressful situation. The scores on this scale were significantly higher for the respondents from Scotland (median score 5.00) than for those from Kerala (median score 2.00). The participants from Scotland were thus more likely to cope by trying to control their emotional impulses. This may reflect the differing degrees of overall distress experienced by the respondents, as well as differing cultural values and expectations regarding self-control.

Tension Reduction

The Kerala and Scotland samples did not differ significantly on this scale. They thus appeared equally likely to use strategies such as exercise, relaxation, or other strategies aimed at reducing their feelings of tension and anxiety. Since using these strategies does not require any additional resources or relationships, the two groups may have had equal access to these behaviours as coping strategies.

Self Blame

For this scale, the respondents from Kerala (median score 1.00) earned higher scores than the respondents from Scotland (median score 0.00). The Kerala respondents were more likely to criticize themselves for the problems they were experiencing. It is possible that this difference reflects the climate of stigmatisation and rejection experienced by the Kerala respondents. Perhaps they were internalising some of the negative stereotypes about HIV and AIDS that are so prevalent in their culture.

Distancing/Detachment

Again, the scores on this scale were significantly higher for the respondents from Scotland (median score 6.00) than for the respondents from Kerala (median score 3.00). This suggests that the respondents from Scotland were more likely to cope with the stress of caring for a family member with HIV/AIDS by seeking emotional distance from the problem. This could be accomplished by withdrawal or by refusing to think too much about the problem. This difference might also reflect cultural differences in the value placed on detachment and emotional distance. It is also possible that the Kerala respondents did not feel that emotional distance was an option for them, since their problems were so far-reaching and overwhelming.

Escape/Avoidance

The Kerala and Scotland samples did not differ significantly on this scale. They thus appeared equally likely to cope by trying to escape from the problem in some fashion. It had been expected that the individuals in Kerala might score higher on this measure, because of cultural beliefs in the role of fate or karma. This difference was not evident, however. The lack of a significant finding here may reflect the small sample sizes, but it may also be the case that the Escape/Avoidance scale does not actually capture the mindset that is prevalent for individuals who believe in karma. It is also possible that people in difficult situations, regardless of culture, tend to be somewhat fatalistic, and thus differences were not evident.

This section has explored the differences between the respondents in Kerala and those in Scotland on the individual scales of the WOC. Taken together, these results suggest that the respondents in the two settings were using somewhat different strategies to cope with the stresses associated with caring for a family member with HIV/AIDS. These differences may reflect cultural differences, as well as differences in the resources available to the carers. The next section explores the impact of caring on the mental health of the participants, and thus gives some insight into the effectiveness of the coping strategies used by the carers.

Mental Health Problems in Kerala and Scotland

Median and Range of Scores for Mental Health Problems

As mentioned earlier, the respondents completed the Self Reporting Questionnaire (World Health Organisation, 1994), which consists of 20 items that describe various non-psychiatric mental health symptoms. Respondents were asked to indicate "Yes" to an item if they experienced the symptom described and "No" if they had not experienced the symptom. The items were scored 1 for "Yes" responses and 0 for "No" responses. The scores were then summed to obtain a total Mental Health Problems score. The median and range of scores for the Mental Health Problems scale are presented below in Table 16.

Table 16
Median and Range of Scores for Mental Health Problems

	Kerala (n=23)		**Scotland (n=5)**	
	Median	Range	Median	Range
Mental Health Problems	12.00	3 to 20	5.00	1 to 14

The median SRQ scores in Kerala and Scotland indicate that the respondents in each setting are reporting a number of mental health symptoms. The significance of these scores in absolute terms is difficult to determine. There are no clear recommendations as to a cut-off score for the SRQ (Beusenberg & Orley, 1994), and several different scores have been reported in the literature. The reported cut-offs for significant mental health problems have ranged from as low as 3–4 to as high as 11–12. It can be noted that the median score of 12 reported by the Kerala sample would meet even the highest of the cut-off scores reported in the literature, while the median score of 5 for the Scotland sample would exceed the lowest reported cut-off score. This suggests that the mental health problems reported by the respondents indicate a level of mental health problems that is moderately significant for the Scotland sample and very significant for the Kerala sample. In the next section, the scores for the carers in the two settings will be compared.

Comparison of Mental Health Problems

Inspection of Table 16 shows that the Kerala sample earned a median score for Mental Health Problems that was much higher than that of the Scotland sample. This difference was evaluated for statistical significance using the Mann-Whitney U Test. The results of the test are presented below in Table 17. It can be seen that the difference is statistically significant; however, the results should be viewed with some caution because of the small number of respondents in the Scotland sample.

Table 17
Mann-Whitney U Test for Mental Health Problems

	Mann-Whitney U	**Significance (two-tailed)**
Mental Health Problems	20.50	.026

The data suggest that the respondents in Kerala are experiencing considerably higher levels of distress than the respondents in Scotland. This difference may reflect a variety of factors, including in particular the social and economic differences between the individual in the two settings. The carers in Kerala were faced with multiple problems and stresses that were not as severe for the carers in Scotland, including severe poverty and harsh stigmatisation and rejection. Their lives thus seem to be much more stressful and difficult than the lives of the carers in Scotland, and their general level of distress may reflect this difference. As mentioned earlier, they also showed evidence that they had fewer coping strategies available to them, and were thus less able to mitigate the effects of the stress they experienced.

The previous sections have presented comparisons of the Kerala and Scotland settings in terms of coping strategies and mental health problems. In the next section, the relationships among these variables will be explored using correlational analyses.

Relationships among Community Setting, Coping, and Mental Health Problems

It can be seen from the above analysis that the respondents in Kerala and Scotland experience very different levels of distress as they cope with the situation of caring for a loved one with HIV/AIDS. The roles of community setting and coping strategies will now be examined to determine the relative influence of these factors on the respondents' overall level of distress. The demographic factors of gender of the carer and education of the carer will also be considered, along with the health status of the HIV-affected family member. Due to the small sample size involved in this study, these data should be considered exploratory.

Correlations

Table 18 presents the correlations among the selected variables. Several significant relationships are evident. The relationships in some instances are quite strong. The squared correlation coefficients (R^2) are interpreted as indicators of the amount of variance accounted for by a particular relationship, and some of the relationships found in the data are impressive.

Community setting is significantly related to several coping strategies, including Problem Focused Coping ($R^2 = .24$), Positive Reappraisal ($R^2 = .49$), Seeking Social Support ($R^2 = .29$), Self Controlling ($R^2 = .58$), and Distancing/Detachment ($R^2 = .25$). The correlations reported here are simply another way of quantifying the relationship between Community Setting and coping strategies, which was already demonstrated in Table 15, where the median scores between the two communities were compared and found to differ significantly on the same scales.

Community Setting is significantly related to Mental Health Problems (R^2 = .22). Two coping strategies, Problem Focused Coping (R^2 = .40) and Seeking Social Support (R^2 = .28), also exhibit significant relationships with Mental Health Problems. In the case of Problem Focused Coping, the relationship is particularly strong. Both of these relationships are negative, indicating that greater use of these coping strategies is related to lower incidence of mental health problems.

Gender of the carer is related to Mental Health Problems (R^2 = .34), but shows no relationship with the other variables. The only significant relationship for education of the carer is with availability of supportive counselling (R^2 = .23). Individuals with more education report greater availability of counselling. Surprisingly, Health Status of the HIV-affected family member is not related to any of the other variables.

Finally, availability of counselling is correlated with two of the coping measures (R^2 = .23 for Positive Reappraisal, and R^2 = .27 for Self Controlling) but with none of the other measures.

Table 18. Correlations of community, demographic, coping, and mental health problems (N=28)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Community Setting	–	.05	.46	.06	-.63	.49	.70	.03	.54	.76	.12	-.37	.50	-.14	-.47
2. Gender		–	.21	-.04	-.09	-.19	.27	.24	-.20	.09	-.23	.35	.22	.20	.48
3. Education			–	.01	.48	.17	.28	-.14	-.03	.34	-.06	.03	.22	.11	-.10
4. Health Status				–	.05	-.05	-.08	-.05	-.10	-.10	-.18	-.01	-.05	.05	.19
5. Availability of Support					–	-.17	-.43	.08	-.37	-.52	-.06	.20	-.30	-.22	.20
6. Problem Focused Coping						–	.40	.30	.64	.38	.40	-.40	.30	-.39	-.63
7. Positive Reappraisal							–	.25	.48	.67	.09	-.38	.43	-.22	-.20
8. Accepting Responsibility								–	.45	-.08	.31	-.14	.36	-.03	-.12
9. Seeking Social Support									–	.36	.37	-.61	.54	-.36	-.53
10. Self Controlling										–	-.07	-.03	.41	.02	-.31
11. Tension Reduction											–	-.42	-.24	-.26	-.27
12. Self Blame												–	-.12	.48	.36
13. Distancing/Detachment													–	.15	-.20
14. Escape/Avoidance														–	.29
15. Mental Health Problems															–

Note. Correlations with a magnitude greater than .37 are significant at the .05 level. Correlations with a magnitude greater than .48 are significant at the .01 level.

The lack of correlation among some of the variables was somewhat surprising. In particular, the lack of gender differences in coping strategies seems surprising. This result may reflect the fact that the samples were mostly female, and therefore did not really have enough males for differences in coping styles to be apparent. It would have perhaps provided positive correlations if the sample had consisted of an equal gender balance. The lack of correlations between education and any of the coping measures is also somewhat surprising. Some of the coping strategies seem more suited to persons with higher education; however, no differences in coping strategy were detected. Again, this may reflect the small size of the samples involved.

The measures of the various coping strategies show a number of correlations, which may be partly due to the fact that they were all measured by the same instrument. Problem Focused Coping is correlated with all of the other coping measures except for Accepting Responsibility and Distancing/Detachment. In the case of Self Blame and Escape/Avoidance, the correlations are negative, suggesting that respondents who report higher levels of Problem Focused Coping rely less on Self Blame and Escape/Avoidance. In the case of the other measures, the relationships are positive, indicating that respondents who engage in Problem Focused Coping also rely on strategies such as Seeking Social Support, Self Control, and Tension Reduction. As mentioned earlier, Problem Focused Coping also has a strong negative relationship with Mental Health Problems. It appears that the tendency to use this strategy reflects a flexible approach to dealing with stress. It may also reflect the greater availability of physical, social, and emotional resources for coping.

The coping strategy of Self Blame also presents some interesting relationships. Self Blame shows negative relationships with a number of other coping strategies, including Problem Focused Coping, Positive Reappraisal, Self Controlling, and Tension Reduction, as well as a positive relationship with Escape/Avoidance. Participants who relied on this strategy seemed to have relatively few other strategies available to them, apart from trying to escape their problems. Perhaps they blamed themselves because they had few alternative ways to deal with the stress they were experiencing. Self Blame also showed a (marginally significant) positive relationship with Mental Health Problems, indicating that those who blamed themselves experienced more mental health disturbance than those who did not. The strategy of self blame thus seems to be ineffectual in preventing the negative consequences of stress in this situation.

As mentioned earlier, these correlational relationships should be viewed with some caution. Correlations are dependent on the size of the sample being analysed. The smaller the sample size, the more likely that a few unusual scores, for just a few of the respondents may cause the correlations to be “imbalanced” in some way. As the number of respondents goes up, this problem is less pronounced, because no one respondent’s set of scores has that much influence by itself. So correlations tend to get more stable as the number of participants increases. As a general rule, the more respondents in a study, the easier it is to get statistically significant correlations.

The correlations shown above suggest a number of interesting relationships among the data, but as correlations, they cannot provide evidence of causal relationships. However, the data are consistent with other studies that show relationships among measures of stress, coping (Folkman & Lazarus, 1985) and mental health (World Health Organisation, 1994). In the next section, the relative importance of the various variables will be examined using regression analyses.

Regression Analyses

Regression is a statistical technique based on correlation. It essentially looks at a combination of independent variables to see how well they predict a given dependent variable. Since correlations can be bi-directional (that is, if A is correlated to B, then B is equally correlated to A), the choice of which variables are independent variables and which are dependent variables is somewhat arbitrary. The strategy utilised by the researcher was to choose dependent variables that would logically be the result or outcome of the independent variables in some way. In this study, the most logical dependent variable is Mental Health Problems. In essence, with the regression analyses, the question being asked is which of the other things measured can be used to predict whether the respondents will exhibit problems as rated on the Mental Health Problems measure. Another possible dependent variable is Problem Focused

Coping, which differed significantly between the two settings. One additional regression analysis was done to explore elements that might predict this coping style.

Several regression analyses were completed, in order to explore relationships among the variables that might predict mental health outcome among carers. Due to the small sample size involved in this study, the data should be considered exploratory and a cautious approach taken when drawing conclusions. Further studies with a larger sample would be necessary in order to confirm any of the relationships described below.

Demographics, Situation Variables, and Mental Health Problems

As a first step in understanding the factors that influence the mental health outcome of family carers, a number of variables related to circumstances of the carers were examined. These include gender of the carers, community setting (Kerala versus Scotland), health status of the HIV-affected family member, and availability of supportive counselling. Gender of the carer was evaluated because this factor often influences mental health in the general population. Community setting, health status, and availability of counselling were included because these reflected important practical aspects of the lives of carers in this study. A hierarchical regression model was used, in order to consider the variables in order of their presumed importance.

Table 19 shows the results for the hierarchical regression analysis. Community setting was chosen as the first independent variable to be entered because of the vast differences between Kerala and Scotland. Gender was entered at the second step. Health of the HIV-affected individual and availability of counselling were entered together at the third step, because there is no theoretical basis for ordering these two variables. The resulting regression equation accounted for a significant proportion of the variance in Mental Health Problems (Adjusted $R^2 = .47$; $p < .01$). Setting and gender each made significant independent contributions to Mental Health Problems; however, neither health status nor availability of counselling was a significant predictor.

Table 19
Summary of Hierarchical Regression Analysis for Variables Predicting Mental Health Problems (N = 28)

Variable	B	SE B	B
Step 1			
Community Setting	-7.70	2.32	-.60*
Step 2			
Gender	5.82	1.60	.51*
Step 3			
Health Status	2.50	1.40	.25
Availability of Counselling	-1.46	1.86	-.14

Note. Adjusted R^2 = .19 for Step 1; ΔR^2 = .26 for Step 2 ($p < .01$); ΔR^2 = .07 for Step 3.

*$p < .05$.

These data suggest that the mental health of the carers was greatly affected by the community in which they lived. Gender also played a role; females were more likely to report mental health problems than males. Studies of the general population usually find that females report a higher incidence of mental health problems, but these data may also reflect the unique stresses on female caregivers, particularly in the Kerala setting.

Coping and Mental Health Problems

A number of the coping measures are significantly correlated with Mental Health Problems, and therefore it seems appropriate to assess the relative contribution of these coping measures to Mental Health Problems. To this end, a stepwise regression analysis was performed, with Mental Health Problems as the dependent variable and the scores for the nine Ways of Coping scales as the independent variables. An exploratory approach was taken; hence no particular order of importance was assumed for the nine coping measures.

The results of the analysis are presented in Table 20. The resulting regression equation accounts for a significant proportion of the variance in Mental Health Problems (Adjusted $R^2 = .38$; $p < .01$). Of the nine coping measures, only Problem Focused Coping made a significant contribution to the variance in Mental Health Problems. The other coping measures were thus excluded from the model.

Table 20
Summary of Stepwise Regression Analysis for Coping Variables Predicting Mental Health Problems (N = 28)

Variable	B	SE B	B
Problem Focused Coping	-1.52	.36	-.63*

Note. Adjusted R^2 = .38. Positive Reappraisal, Accepting Responsibility, Seeking Social Support, Self Controlling, Tension Reduction, Self Blame, Distancing/Detachment, and Escape/Avoidance were excluded from the model.
*$p < .01$.

Based on this analysis, it appears that Problem Focused Coping is the best predictor of Mental Health Problems among the nine coping measures. This finding suggests that taking a direct approach to problems has a better impact on overall mental health. This finding is consistent with other studies that show apparent benefits of a problem-focused approach (Folkman & Lazarus, 1985). It should be remembered, however, that correlations cannot show causality. Thus, it is possible that individuals who are functioning better are more likely to use problem-focused coping to manage stressful experiences.

Setting, Gender, Coping, and Mental Health Problems

The analysis discussed in this section combines the variables that have been found to predict mental health outcome thus far. These include setting (Kerala versus Scotland), gender of the carer, and Problem Focused Coping. Hierarchical regression analysis was used, with setting entered in the first step, gender entered in the second step, and Problem Focused Coping entered at the third step.

Table 21 presents the results of the regression analysis. The resulting regression equation accounted for a significant proportion of the variance in Mental Health Problems (Adjusted $R^2 = .56$; $p < .01$). When all three of these variables are included in the equation, gender and Problem Focused Coping make significant independent contributions to the variance in Mental Health Problems; however, the independent contribution of community setting is no longer significant, though it does approach significance ($p < .07$). This likely reflects the fact that setting is significantly correlated with Problem Focused Coping. It is therefore difficult to sort out the independent contribution made by each of these factors.

Table 21
Summary of Hierarchical Regression Analysis for Setting, Gender, and Coping as Predictors of Mental Health Problems (N = 28)

Variable	B	SE B	B
Step 1			
Community Setting	-3.71	1.94	-.29
Step 2			
Gender	4.78	1.52	.42**
Step 3			
Problem Focused Coping	-0.98	0.37	-.41*

Note. Adjusted $R^2 = .19$ for Step 1; $\Delta R^2 = .26$ for Step 2 ($p < .01$); $\Delta R^2 = .12$ for Step 3 ($p < .05$).

*$p < .05$; **$p < .01$.

These findings suggest the importance of both gender and problem focused coping for carers who are managing the stress of caring for a loved one with HIV. Efforts to assist family carers may be enhanced by paying attention to the role of gender. The significant finding for Problem Focused Coping is also notable, since this type of coping strategy may be something that could be taught to carers. Interventions that help family carers address their problems more directly may prove beneficial in minimizing the mental health impact of caring for a loved one with HIV/AIDS. In the next section, the possible impact of demographic or situation variables on Problem Focused Coping will be explored.

Predictors of Problem Focused Coping

Since Problem Focused Coping was found to be an important predictor of mental health outcome, further exploration of this variable seemed warranted. A regression analysis was thus undertaken, to determine whether selected demographic and situation variables were useful as predictors of Problem Focused Coping. With Problem Focused Coping as the dependent variable, gender, education, and age of the carer were entered as independent variables. The results of this analysis are presented in Table 22.

Table 22
Summary of Regression Analysis for Gender, Education, and Age as Predictors of Problem Focused Coping (N = 28)

Variable	B	SE B	B
Gender	-.75	.89	-.16
Education	.61	.43	.27
Age	.88	.43	.38

Note. Adjusted R^2 = .12 (ns).

Owing to the small sample size in this study, the researcher would like to point attention to the fact that the correlations are likely to be unstable; a researcher who asks the same questions in the same populations but has more respondents might get very different results. Additionally, the more independent variables are present in the study, the larger the number of respondents is needed in order to achieve stable relationships among the variables. Therefore, in this study, it was not statistically appropriate to try to use every one of the variables as independent variables in regression analyses, as the sample size was small.

These data suggest that none of the selected variables is a significant predictor of Problem Focused Coping. This result may reflect the small sample size and relative lack of variability of the sample. It is also possible that other factors not measured in this study have an important influence on Problem Focused Coping.

This section has explored the relationships among the variables using regression analyses. The influences of setting, gender, and problem focused coping on mental health problems were investigated, and it was found that gender and problem focused coping made significant independent contributions, with community setting approaching significance. The influences of age, gender, and education on problem focused coping were then examined; however, none of these variables had a significant influence. The likely reasons for these findings were also explored.

Conclusion

The results for the Ways of Coping measures suggest that the carers from Scotland utilized a wider array of coping strategies than did the carers from Kerala. These strategies included direct strategies aimed at dealing with the source of their stresses as well as indirect strategies aimed at managing their emotional reactions to the problem. Having a wider array of coping strategies available may confer an advantage on the carers from Scotland as they deal with the stress of caring for a family member with HIV/AIDS.

These differences may reflect the wider array of resources available to the carers in Scotland. They could use more means to cope because the necessary elements were more available to them. Although the WOC was modified to reflect the different cultural values of the Indian sample, it is possible the scale still does not adequately capture the coping strategies used by people in India, and thus they appeared to have few coping strategies because the strategies they actually used were not included in

the measure. Conversely, it may be an accurate reflection of the reality that carers in Kerala due to the limited resources available to them found it difficult to cope with caring for their family member living with HIV/AIDS. The qualitative data may thus provide better insights into the coping strategies used by the individuals in Kerala.
The results obtained for mental health problems suggest that the burdens of caring are having a significant impact on the carers in both settings. The carers are reporting a range of mental health problems, particularly in the area of anxiety and depression. The carers in Kerala are faring significantly worse than those in Scotland. This may reflect the harsher conditions that the carers in Kerala are experiencing.

The exploratory correlation and regression analyses suggest a number of interesting relationships among coping strategies, gender, and mental health problems. In particular, gender and problem focused coping emerge as important predictors of mental health outcomes. Being female increases the likelihood of reported mental health problems, while the use of problem focused coping seems to reduce the number of reported mental health problems. These relationships will be discussed further in the next chapter.

Although the current study is primarily qualitative in nature, the quantitative analyses outlined here were included in order to provide a more complete picture of the circumstances for family carers in Kerala and Scotland. The results suggest some important differences between family carers in the two settings, in terms of coping strategies as well as mental health consequences of assuming the burden of caring. Taken together, the exploratory data presented in this chapter suggests the need for further investigation into the relationships among coping, community setting, gender, and mental health problems.

The next chapter will discuss each of the qualitative and quantitative findings in turn, with attention to the ways these findings fit into the existing body of literature.

CHAPTER 8: DISCUSSION AND SYNTHESIS

Introduction

The previous two chapters have presented the qualitative and quantitative findings of the study. They describe the circumstances experienced by the carers, as well as their efforts to cope with the burdens of caring and some of the consequences of those burdens. This chapter will discuss these findings in relation to the existing literature and will highlight the cross-cultural dimension of the research by pointing to the experiences unique to each context. The chapter will also discuss the influence of socio-cultural-developmental context on the lives of the family carers from Kerala and Scotland.

The first section looks at the experiences of caring, coping, and mental health. It summarises the relevant qualitative and quantitative findings. The next section explores the three unifying concepts of struggle, commitment, and resilience. The literature in relation to the theoretical underpinnings of these concepts is also explored in this section. The third section proposes a model of family caring in HIV and AIDS. Finally, the last section points the way to the conclusions presented in the next chapter.

This chapter draws together the six themes that emerged from the analysis of the data. Upon reflection of these themes together, a synthesis began to develop. From this synthesis emerged the three concepts of struggle, commitment, and resilience that seemed to run through the narratives of the carers. These three concepts provide a theoretical framework against which the experiences of family carers of persons living with HIV/AIDS in different contexts of development can be understood.

The concepts of struggle, commitment, and resilience contribute to a deeper understanding of the phenomenon of family caring and HIV/AIDS. This understanding in turn helped the researcher to create a model of family caregiving in HIV/AIDS, which combines both the qualitative and quantitative findings of the study. It is important to note that, while the qualitative findings provided the foundation for generating a tentative theoretical model, the quantitative findings helped to support the qualitative findings, and in turn contributed to the development of the proposed model. Thus, in doing so the research generates theory (Glaser & Strauss, 1967) that contributes to a further understanding of the phenomenon of family caring of persons with HIV/AIDS.

Experiences of Care, Coping, and Mental Health

Summary of Relevant Findings

The qualitative findings comprise six themes that were discovered through the process of analysis described previously. These themes included the many issues that accompanied the advent of HIV in the carers' lives; the physical, emotional, social, and economic experiences of caring; the communication, sexual, and childrearing family dynamics that arose in caring; the special experiences of carers who were positive themselves; the role of informal social support networks; and the contributions of formal support services. The use of qualitative methods facilitated the discovery of the processes relevant to the lived experience of the carers. They enabled the researcher to obtain thick description of phenomenon in both the research contexts. Additionally, they both elicited and added power to the unheard voices of the carers (Ungar, 2003).

The quantitative findings included some exploratory analyses that examined the coping strategies used by respondents in Kerala and Scotland as well as the mental health problems experienced by the respondents. The results indicated that the Kerala and Scotland respondents relied on decidedly different strategies when coping with the stresses related to family caring. The Scotland respondents were significantly more likely to use the strategies of problem-focused coping, positive reappraisal, seeking social support, self controlling, and distancing/detachment. The only coping strategy that was endorsed at a higher level by the Kerala respondents was the strategy of self blame. These results suggest that the Scotland respondents had a wider array of coping strategies available to them, perhaps reflecting the greater availability of resources. These quantitative findings seem to fit well with the qualitative findings regarding the resources and supports available for the carers in the two settings.

The greater tendency to use self blame on the part of the Kerala respondents may reflect their helplessness in the face of overwhelming obstacles, as well as internalization of the negative and stigmatising attitudes that prevail in their community. It should be remembered, however, that a single finding such as this one may not be reproducible in a larger sample, and indeed, there did not seem to be parallel qualitative evidence for this finding.

The findings for mental health suggest that the respondents in both settings experienced significant mental health problems, particularly symptoms suggesting depression and anxiety. The Kerala respondents reported significantly more of these problems than the Scotland respondents. Exploratory regression analyses indicated that gender, problem-focused coping, and setting were all significant predictors of mental health problems. Females, those from Kerala, and those who relied less on problem-focused coping were more likely to experience mental health problems.

The use of quantitative research methods enabled the researcher to develop a more objective understanding of the respondents' coping strategies and mental health, which could be tied to the existing literature in this field. Moreover, the quantitative findings also helped to validate the qualitative findings when parallel results were obtained.

Discussion of Qualitative Findings

The Advent of HIV

The time of discovering that a loved one was infected with HIV emerges as a particularly memorable and trying experience for the respondents in this study. A number of respondents, particularly those in Kerala, had little or no awareness of HIV and AIDS before they learned that a loved one was infected, and thus they were faced with a plethora of confusing and distressing issues all at once. Shalini's recollection of that point in time echoes both the lack of awareness and confusion expressed by other carers in Kerala. She said: *"I was totally perplexed about what HIV or AIDS was, was it two illnesses or what, or what not"*.

Reidy (1997) notes that many carers learn that a loved one is infected with HIV at the same time as they learn of the infected person's lifestyle, which may include homosexuality, drug use, or purchasing the services of a sex worker. These discoveries may be shocking and distressing for the family carer, and they come at a time when the family is already facing the blow brought by the illness and probable death of the infected person. The accounts of carers in both Kerala and Scotland reflect this. Usha, a carer from Kerala, recalled the terrible anguish she experienced when she realised that her husband's unfaithfulness had led to the situation they were in. Her account reflected her feelings of betrayal against the backdrop of impending loss. She said: *"I felt very badly betrayed that he had lied to me, but I felt even more pained at the thought of him dying"*. Similarly, two carers from Scotland, Trisha and Julia, expressed feelings of angst against the backdrop of imminent bereavement. Julia said: *"I had for sometime suspected that he used them* (referring to drug use) *but when he told me that it had led to him getting the virus I was doubly devastated"*.

Another important aspect of the advent of HIV is the fact that most of the respondents learned of the loved one's infection because that person began experiencing significant medical problems. This would indicate that the infection had been present for some time, and this fact carries with it a number of distressing implications. If the carer was the spouse or sexual partner of the infected person, then discovery of symptomatic HIV in a loved one raised the spectre that the carer was infected as well. Miller and Goldman (1993) and Shaw (1992) point out that the consequence of female carers discovering HIV is potentially devastating. The discovery affects them not only as carers, but as individuals who are at risk of being infected, in their multiple roles in the family and community as mothers, wives, caregivers, educators, and providers. Some carers in Kerala remarked upon the anxiety they experienced at the thought that they might be infected by their husbands. Usha's distress was reflected in her comments. She spoke about her fear of being positive, as she felt rather weak and tired. However, she also spoke of her unwillingness to be tested as that would confirm her fears. She said: *"I cannot afford to lose hope and the will to live because if that happens who will look after my children?"*

In addition to the concerns about their own possible infection, many carers were also facing significant health problems in the infected family member. If the loved one's HIV status was only discovered when they developed symptoms, this meant that the syndrome had already progressed beyond the early stages. Thus the carers could anticipate the increasing debility and eventual death of the infected person. Anticipatory grief refers to the process of grieving before the actual death. The HIV/AIDS epidemic has a prolonged character and hence often leads to anticipatory grief or "pre-death" bereavement (Klein, 1993). The accounts of a few carers in both settings revealed the anticipatory grief that they experienced. The words of one carer in Scotland reflect anticipatory grief she experienced at the thought of her son's imminent death. Kate said: *"It was strange; I began to mourn for him even before he was anywhere near dying".*

Although the early stages of HIV infection may be relatively easy to manage, most of the respondents in this study were unaware of the loved one's HIV infection during the asymptomatic phase. They discovered the HIV infection as the same time that they became aware that the infected member had serious symptoms, and they had no time to adjust to the reality of HIV infection before they were faced with serious and distressing medical symptoms. For example, Sheela, from Kerala, recalled how her husband's diagnosis with kidney problems came to them at the same time when they discovered he had AIDS, so he was already very unwell.

As would be expected, this led to various emotional responses from the carers. The respondents reported a range of emotional reactions to the discovery of HIV which is similar to that reported in the literature. The initial shock or panic is similar to that experienced by family members in relation to learning about other types of chronic or life-threatening illness. But the quality of the emotional reactions to learning about HIV infection in a loved one may be unique, because of the multiple implications of

HIV infection—sexual overtones, possible betrayal, personal risk of infection, and fears of stigmatisation and ostracism. The accounts of several carers bear testimony to this. The words of a carer from Kerala echo the emotions of carers in both settings. Gangabai said: "*This disease is most unusual because not only does it bring death but it also brings shame and fear*". Kelly and Lawrence (1988) have commented on these unique aspects of the HIV pandemic that make for unique emotional reactions.

One important influence on the experience of the Kerala respondents was their generally low level of awareness regarding HIV and AIDS prior to the advent of HIV in their lives. Although the media and the governmental/public health organisations in developed nations such as Scotland have disseminated a good deal of information about HIV/AIDS to the general public, this is not the case in some developing countries. The carers from Kerala had little or no information about HIV/AIDS, and this left them open to the widespread superstition and misunderstanding regarding HIV/AIDS. Thus fear of the unknown and misinformation added to their burdens as HIV entered their lives. The respondents from Scotland all had at least a basic understanding regarding HIV/AIDS, but they too were lacking information. It is likely that many of them may have ignored the information that was available regarding HIV/AIDS until it became an important issue in their lives. This is poignantly revealed in the recent reports which state the alarming increase in the HIV/AIDS incidence in Scotland (Moss, 2004).

The process of becoming a carer was fairly similar for most of the respondents in the study. In most cases, the person who became a carer did so because there were few alternatives. Because of the stigmatising nature of the illness, persons in general want to dissociate themselves from persons with HIV and their families. However, family carers, because of their commitment and natural bonds of love and family, are unable to do so. When the affected person was the carer's spouse, the respondents took on the duties of caring because they were compelled by the circumstances—they seemed to see caring as one more of the duties expected by a spouse. Parents also assumed the caring role as a matter of course. As Bharat (1996) noted in her study, carers took on the burden of care regardless of feelings toward the HIV/AIDS-affected person. A sense of duty compelled them to take on the responsibilities. Feelings of love for the affected person also compelled them to assume the duties of care. As with Bharat's sample, most of the carers in the present study were women. Women have traditionally taken on the caring role when a family member becomes ill.

The Experience of Caring

It has been noted that caring for a family member with HIV/AIDS has an effect on every sphere of the carers' lives (Brown, 1993; Maruin & Boyd, 1990). Certainly the carers in this study mentioned a broad range of effects, including physical, emotional, social, economic, and family relationship concerns.

The most common physical reaction reported by the respondents was tiredness or exhaustion. This is not surprising, given that many of the carers were performing extensive nursing duties for the HIV-affected family member, in addition to the duties that they had performed prior to the advent of HIV in their lives, as well as taking on the duties previously performed by the ill family member. A number of authors (e.g., Brown, 1993; Meyers & Weitzman, 1991; Reidy et al., 1991) have commented on the exhausting nature of the many duties imposed by family caring with HIV-affected patients. A comment made by a carer from Kerala reflects the sheer exhaustion experienced by carers. Sheela said: *"I feel dead tired and exhausted all the time ... sometimes I feel as if my body is just going to break."* These findings are similar to those documented in a large body of literature regarding the negative physical affects of caregiving with other chronic and debilitating illnesses (e.g., Baumgarten, 1989; Schulz et al, 1990). A study by LeBlanc et al, (1997) suggests that the burdens of AIDS caregiving may ultimately compromise the health of the carers themselves. This is particularly true if the carers are themselves infected with HIV.

Other physical reactions reported by the respondents include loss of sleep, loss of appetite, and weight loss. These reactions may also reflect the exhausting physical burden of family care, but they may also be symptomatic of significant depression or anxiety. Given the many threats to well-being and the very real losses experienced by the carers, it is not surprising to find symptoms of anxiety and depression in this sample. Caregivers in general have been shown to be vulnerable to depression (Miller, 1987; Wright et al., 1993), and the stresses of providing care for those with HIV/AIDS have also been related to depressive symptoms (Leblanc et al, 1995). These realities were also evident in the quantitative data, which will be discussed below.

It is important to note that, despite the exhaustion and other discomforts that the carers experienced, they were determined to "go on," to somehow find a way to provide the care needed by their HIV-positive family member. For some, this likely reflects the utter absence of alternatives; however, it also reflects a curious kind of strength or resilience in the face of tremendous hardship. This is echoed in the account of Gangabai, from Kerala, who vowed to be there for her husband, until the end, irrespective of what happened to her.

One of the most predominant emotional reactions of the carers in both settings was worry and anxiety. The many threats to family well-being, along with the many uncertainties of HIV and AIDS, can create an atmosphere that promotes constant anxiety and worry. Brown and Powell-Cope (1991) comment on the toll that uncertainty takes on family carers and others have likened the experience to a "roller-coaster" (Brown, 1993; Gaynor, 1990). Interestingly, carers in both contexts used images of shadows and clouds to describe the incessant nature of the worries/anxieties that the advent of HIV/AIDS brought to their lives. Ann, from Scotland, likened the worries to a shadow that never left her, and Sajini and Bindu, from Kerala, spoke about "black clouds" that followed them.

Another very common reaction was a sense of loss or emotional pain. This finding is very common in the literature related to the impact of HIV. The course of HIV infection is marked by a series of losses. The diagnosis of HIV/AIDS itself may result in sudden and dramatic grief and pain over a variety of losses (Sherr, 1995). Losses associated with HIV/AIDS pervade every facet of an affected and infected person's life (Teguis & Ahmed, 1992). Social losses encompass loss of privacy, life style, relationships, and peer group in addition to experiences of ostracism and stigmatisation. Psychological losses include self-esteem, innocence, sense of stability, future hopes and dreams, self-image, independence, life, decision-making, certainty, and sex. Finally the financial losses include loss of job, health care, and security. Loss constitutes a crucial element of the life experiences of persons with HIV/AIDS, and thus may have a tremendous effect on the changes they undergo and the transitions they make.

HIV/AIDS brings mental, social, and spiritual pain and suffering to an individual. While physical pain is difficult to control, it can be temporarily alleviated through artificial means. However, there is no artificial alleviation of mental, social, and spiritual pain. Saunders et al. (1995) suggest that persons with HIV/AIDS and their families have to face the pain and anguish to emerge from this time of crisis. They reiterate that facing the deepest issues in anguish helps the person to come to terms with his pain and develop strengths that help in living with HIV/AIDS and facing the future. They also suggest that surprising growth can be achieved within a short time, as in other situations of crises.

Sherr (1995) suggests that the "burden of grief is the silent backdrop that looms behind the high profile HIV/AIDS epidemic" (p. ix). Some of the complex psychological issues experienced by persons infected and affected with HIV/AIDS include grief, bereavement, and the complex processes of death and dying. The experience of grief is widespread and profound in persons with HIV/AIDS, their families, and their communities.

Faced with repeated reminders of the impending death of the HIV-affected family member, as well as with all of the other losses, associated with HIV/AIDS in the family, it is not surprising that many carers develop a sense of powerlessness, isolation, and hopelessness (Reidy, 1997; Spiegel & Meyers, 1991). The accounts of carers in both contexts poignantly reflect this reality, particularly for the carers in Kerala. This burden was made even more intolerable by the isolation, stigmatisation, and ostracism they experienced. Many carers lived in fear that the HIV status of the loved one would be discovered and would lead to their expulsion from their homes. This social rejection leads to a further sense of loneliness, isolation, and hopelessness for many carers (Carmack, 1992). The accounts of Sheena, Gangabai, and Sheela movingly describe this painful reality for carers in Kerala; described by them as "a living hell". It is tragic that this aspect of their misery could have been alleviated by adequate education of the populace, to diminish the misunderstanding and stigmatisation attached to HIV and AIDS.

A report by Human Rights Watch (2004) poignantly illustrates these aspects of living with HIV/AIDS. They cite an incident in July 2004 where two HIV-positive children from Kottiyoor, a village in Kerala, were thrown out of a school until the government intervened and had them readmitted in to a government school. However, even in that school they were segregated from other students and taught by a specially appointed teacher. Another incident in Thiruvananthapuram, Kerala (in November 2003), which they cited, reflected the researcher's own experience. They found that some of their respondents were willing to meet only outside of their neighbourhoods for fear that their visit would reveal their HIV-positive status to their neighbours. One respondent said that if the community discovered his status, he would commit suicide, because he feared that he would be stoned to death.

In the vast majority of communities in Kerala, HIV/AIDS remains highly stigmatised and poorly understood. Stigma permeated different aspects of the carers' lives, rendering them unable to seek support and thus leading to further isolation. Crewe et al. (2002, p. 23) note:

> *Stigma remains one of those intractable social problems that will require a determined effort to make sure that we are able to address it at every level and redress the multiple wrongs that have been and are inflicted on people with HIV and AIDS and their families.*

AIDS-related stigma creates barriers for persons living with HIV/AIDS and their families. Stigma prevents these individuals from fulfilling their human rights and also acts as a barrier to effective HIV programming. It is a "multi-layered process of devaluation" that tends to reinforce negative connotations by associating HIV and AIDS with already-marginalized groups (UNAIDS, 2004a, p. 125). Stigma underlies the process of discrimination that serves as a barrier for people who need AIDS-related services, and it sets up conditions in which their human rights are infringed and they are subjected to abuse. The experiences of the carers in this study clearly underscore these ideas. Carers in Kerala lived in constant fear that the presence of HIV/AIDS would be discovered and that they would be therefore lose their homes, their livelihood, and their relationships with members of the larger community.

While the situation was distressing for many of the carers, a few carers in Scotland commented on a different experience—the acceptance that they had experienced. Their experiences highlight the positive change brought about by greater understanding of HIV/AIDS in the larger community. Acceptance, (as opposed to rejection) by the society of a life-threatening, stigmatising illness such as HIV/AIDS can minimise the stress that carers are already experiencing, albeit marginally. Ann's narration reflects this. She said: *"the acceptance and support that I have received from my family and friends have gone a very long way in helping me to live positively".*

Economic concerns often played a major role in the distress experienced by family carers in both settings. HIV/AIDS places tremendous strain on families who are already limited in resources and economically vulnerable. The time required to care for the HIV-infected family member often made it difficult for the carer to hold down a steady job, and employment concerns were evident for carers in both settings. The costliness of medicines and other supplies necessary for the affected person was also a significant issue. Even in instances where there was substantial support coming from the government, as in Scotland, the process of family caring created many financial burdens.

These findings are similar to those documented in Thailand by Chanpen and Knodel (2001), who examined parents as HIV/AIDS carers. The situation was somewhat more severe for the families in Kerala, due to stigmatisation. Chanpen and Knodel found that the carers in Thailand were able to turn to their support networks for financial assistance as their own economic resources were exhausted; however, the climate of secrecy and stigma attached to HIV/AIDS made this much more difficult for the Kerala families. The accounts of several carers in Kerala reflect this difficult situation. Usha recalled how complicated it was even to hold down a job under the fear that her employers would discover that her husband was suffering from AIDS.

Moreover, the accounts of some other carers from Kerala (Sheena and Maya) highlight the economic problems that carers face, particularly female carers, when their property and inheritance rights are denied in the face of HIV/AIDS in their family. Heyzer (2001) states that HIV/AIDS epidemic has led to a dramatic increase in female-headed households, in which women are called upon to be the main carers. This situation is greatly worsened in patrilineal systems of inheritance that deprive women and their children of their homes and inheritance upon the husband's death. The accounts of a few carers in Kerala bear testimony to this reality.

Property and inheritance laws that discriminate against women contribute to the spread of HIV. When women lose their property rights upon the death of a father or husband, their relatives may seize their property and render the women and children homeless. This loss of possessions may force the women into sex work in order to survive, putting them at a much higher risk of HIV infection than men (Heyzer, 2001). This sort of property discrimination continues even when governments have accepted the principles of the UN Charter, the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child (UNAIDS, 2004a).

Family Dynamics in Caring

The results of this study suggest that family dynamics can be altered in several different ways, both negative and positive at the same time. Some carers reported an increase in togetherness and commitment, much like that suggested by Miller and Goldman (1993). Sheena's account from Kerala reflects the strong bond that she developed with her husband on account of the complete isolation and ostracism they faced from the community. Others noted increases in family tensions, heightened by the atmosphere of worry and threat. The accounts of Usha and Thusha (carers from

Kerala) and Julia from Scotland reflect the increasing tension, anger and resentment that HIV/AIDS brought into their relationships. Julia said: *"my pain at seeing him suffering makes me angry and I tell him off at times"*.

Communication was an issue that was mentioned often by the carers in both contexts. Gaitley et al. (1993) note the many interpersonal issues that arise in dealing with HIV/AIDS, and each of these issues can be difficult to discuss even at the best of times. In the atmosphere of threat, isolation, sense of betrayal, and loss that carers often experience, such communication is even more difficult. Despite these problems, however, many families found a way to communicate frankly, and at times this increased the sense of commitment to the relationship. Carers in Kerala suggested that they had no alternatives but to interact. Being shunned by the community, the only contact carers had was their own loved one with HIV/AIDS, as illustrated in Sheena's case vignette in Chapter 6.

Changes in family roles also arose as issues for the carers in this study, particularly those in Kerala. The illness and incapacitation of the HIV-positive family member often required the carer to assume new roles, and this was not always an easy process. Meyers and Weitzman (1991) and Reidy (1997) mention similar problems with role restructuring, and Heyzer (2001) notes the particular hardship this situation creates for women. In a traditional society like that of Kerala, men take on the role of running the family, and women generally have little knowledge about the financial and other issues that have been the province of the head of household. However, with the advent of HIV/AIDS, these women are forced to take up the responsibilities of the head of household, with little preparation or support for them in this role. The unfamiliarity of this role may bring its own set of hardships for these women.

Another area that was affected by the process of caregiving concerned sexual relationships. In cases where the carer was the spouse of the HIV-positive family member, the risk of transmitting the virus meant that sexual activity had to be altered or curtailed to prevent infection of the carer. Savitri, the wife of an HIV-positive person in Kerala said: *"We cannot try for a child now ... I cannot risk becoming infected myself or infecting my child"*.

Finally, a number of concerns of the carers revolved around children. In cases where both parents were positive, the carers experienced great worry about the future welfare of the children. In addition, some parental carers in Kerala had the dual role of caring for their children and at the same time bringing up the grandchildren. Kumaran said: *"I worry for my daughter's health, but also about who will look after my grandchildren after I am gone"*.

Even when the carer was not infected with HIV, issues related to children were problematic. A carer in Kerala, (Sheela) spoke about the shadow of fear that she had to live under; worrying that sharing her husband's HIV status with her children might inadvertently expose their predicament to the community, leading to unfavourable repercussions. Another area highlighted by some carers in Kerala was the impact of poverty and lack of resources as a result of stretching limited resources to meet the needs of their positive family member as well as those of their children.

Carers Who Were Positive Themselves

As discussed in chapter 6, there were two carers in Scotland who were HIV-positive themselves. The literature documents a number of issues and concerns that arise for HIV-positive carers. These include dealing with signs and symptoms of AIDS itself, social stigma, rejection by family and friends, fear of being sick, possible frequent hospitalizations, and concerns over the long-term guardianship of children (Aranda-Naranjo, 1993; LeBlanc et al., 1997; LeBlanc & Wardlaw, 1999; Reidy et al, 1991). Another issue for HIV-positive carers is the loss of childbearing. Ann, a carer from Scotland, spoke about the pain she experienced because she would never be able to bear a child due to her HIV status. As mentioned earlier, the carers may experience anticipatory grief for the loss of the HIV/AIDS-affected partner, as well as fear and anticipatory grief for their own illness and death.

As explained in Chapter 6, none of the carers in Kerala reported being positive themselves, because they had chosen not to be tested. In India, as in the rest of the world, when treatment for HIV/AIDS is not available and people identified as HIV-positive are discriminated against, people have little incentive to be tested for HIV.

Informal Social Support Networks

The recurring finding in this area was the lack of adequate social support. This lack of support was extreme for the carers in Kerala, many of whom lived in fear that their neighbours would learn about the HIV infection of the affected family member and turn against the family. Family carers, especially in developing countries, provide invaluable support to HIV positive persons amidst the situation of poverty. Accounts of carers from Kerala highlighted instances where people were willing to be of help to HIV affected families, but were afraid of societal reprisal. Due to the extreme stigma and widespread discrimination in Kerala, there existed a culture of silence that prevented them from seeking social support. These carers carried a burden of secrecy, which made it impossible for them to talk with friends or neighbours about their situation. At times this burden of secrecy included members of the extended family. This sense of isolation has been found by other researchers such as Carmack (1992). The experiences of the carers in Scotland were more varied. Some indicated that they received support from various sources, but some still experienced a lack of support for their needs.

The enormity of the tasks faced by family carers may have made any level of social support seem inadequate at times. While research has demonstrated that various forms of social support can alleviate the burdens of caring for a family member with HIV/AIDS, (Hart et al., as cited in Reidy, 1997; McGough, 1990), the enormity of the task may make any level of support seem inadequate. The lack of social support may have a particular impact on carers by impairing their efforts to cope (Thoits, 1986).

Formal Support Services

The findings in this area demonstrate the undeniable link between the HIV epidemic and issues of development. The carers in Scotland could name a number of governmental and voluntary resources that provided assistance to them in coping with the demands of caring for an HIV-affected family member. Even these resources seemed inadequate, however. They highlighted the need for information, respite, and general support services. For the respondents from Kerala, virtually no formal support was forthcoming. This finding illustrates the ways that the problem of HIV/AIDS is interwoven with issues of development.

As discussed in Chapter 3, poverty plays a significant role in perpetuating underdevelopment and undermines the efforts to reduce the suffering engendered by the HIV/AIDS epidemic. While poverty in many parts of the developing world is absolute, it is important to stress that there are parallels in the developed world. Poverty has been an issue of debate in Scotland, and a report by Child Poverty Action Group (Howard et al, 2001) has shown that three of the most socially deprived and poor areas in the United Kingdom are in Scotland: in the Shettleston, Springburn and Maryhill areas of Glasgow. Additionally another study undertaken by Bristol and London University concluded that almost one in 10 in the United Kingdom has experienced conditions of absolute poverty: without the basic human necessities of enough food, safe drinking water, and proper sanitation (Duckworth, 2001). Thus, in the context of HIV/AIDS caring, poverty remains a major issue to local development initiatives such as formal support services for carers.

Discussion of Quantitative Findings

Coping Strategies in Kerala and Scotland

Coping is the process by which a person adjusts to stress and tries to mitigate its negative effects. People can use any of a number of different strategies for coping, depending on the nature of the stress, the availability of resources, and their own preferences, habits, and abilities. The primary finding in this area concerned the differences in coping strategies used by the participants in Kerala and Scotland. The participants in Scotland used a much broader array of coping strategies than the

Kerala participants, including both problem-focused and emotion-focused strategies. This difference may reflect the differences in resources available to the family carers in the two settings. Many coping strategies require that the carer have access to certain resources. For example, a carer cannot use social support as a coping strategy unless there are people available to provide the necessary support. Similarly, the carers cannot look for advice unless such advice is available. For the Kerala respondents, the array of resources was much smaller, and thus they used fewer strategies because many of the strategies were impossible for them. In particular, the atmosphere of secrecy and threat may have prevented them from seeking many forms of assistance from others, out of fear that they would suffer severe social consequences if the HIV status of the family member were revealed.

Patterson (1988) has discussed the importance of coping strategies for families dealing with illness of a family member, and has pointed out the importance of balance between the demands on the family and the family's resources. In the case of the Kerala participants in this study, there was a clear lack of balance between the demands and the resources. This imbalance could signal a failure of coping efforts for many of the family carers in Kerala.

One coping strategy that may be particularly influenced by the availability of resources is problem-focused coping. Problem-focused coping involves taking direct steps to eliminate the source of stress. In the case of caring for a family member with HIV/AIDS, such direct steps might include obtaining medicines and treatment to reduce the symptoms of illness in the affected family member. Getting a job or applying for financial aid to alleviate financial strains associated with the illness would be another example of problem-focused coping. It can be seen that problem-focused coping often requires access to resources, and the lack of these resources may explain why this strategy was not used more often by the carers in Kerala. They may have wished to take direct steps to reduce the stresses they were experiencing, but direct action may not have been an option.

It is also interesting to note the one coping strategy in which the Kerala respondents earned higher scores than the Scotland respondents—self blame. This coping strategy involves dealing with stress by thinking of it as something that is deserved. The Kerala respondents were more likely to adopt this attitude than the Scotland respondents. This may reflect internalisation of the negative attitudes towards HIV/AIDS that are prevalent in the community. Even though the carers have done nothing to deserve the burden that they bear, they nonetheless seem to see themselves as blameworthy. The belief in fate or karma might also play a role in this phenomenon. Karma, or the law of cause and effect, forms an integral part of Hindu philosophy. The Concise Oxford Dictionary of Current English defines it as the "sum of person's actions in one of his successive states of existence, viewed as deciding his fate for the next". Perhaps the carers felt that they were better able to accept the burdens they carried because they saw them as ordained by karma.

Mental Health Problems

The findings for mental health problems in this study indicate that the carers are experiencing a number of significant problems, particularly in the Kerala setting. These findings are very consistent with previous research, which has shown a high degree of symptoms of emotional distress among carers in general (Baumgarten, 1989; Schulz et al, 1990; Wright et al, 1993) and in particular among carers for persons with HIV/AIDS (Leblanc, et al, 1995; Lennon et al, 1990; Pearlin et al, 1988). These findings are not surprising, given the distressing nature of caring for an HIV/AIDS patient and the many sources of worry and distress inherent in this circumstance. Nowhere more poignantly was this reflected than in the account of Sheena (described in the vignette in Chapter 6) who carried a sachet of poison in case life became so unbearable that she needed to end her life.

A large body of literature has already documented the relationship between stressful experiences and experienced psychological distress, particularly depressive symptoms and negative mood (for reviews, see Kessler, Price, & Wortman, 1985 and Thoits, 1986). The level of symptoms was particularly high for the participants in Kerala, where the respondents earned a median score that is at or near even the most stringent cut-off for significant mental health problems on the Self Reporting Questionnaire (Beusenberg & Orley, 1994). The carers in Kerala appear to be a particularly vulnerable population, who are feeling the effects of particularly difficult conditions, such as the high level of stigmatisation, the lack of medical and support services, the lack of medication, and the high level of poverty among the carers. The findings of this study suggest that the cost of caring is particularly high for these carers, who often have no alternative but to provide care.

Empirical studies in developed countries suggest that caregivers with higher levels of social support are less likely to experience negative outcome (Turner, Pearlin, & Mullin, 1998). Social resources can provide emotional comfort and practical support; reduce social isolation; and offer humour, recognition, and encouragement (Maslach & Goldberg, 1998). They also can be a valuable source of new information and insights (Driedger & Cox, 1991). In Kerala, where little, if any, of this type of support was available, the reported problems of the carers illustrate what happens to people who must face the burdens of caring without such supports. Carers in Kerala live in a culture of silence, in a society where traditional values of compassion and kindness towards the ill family member were undone by the appalling stigma and discrimination associated with HIV/AIDS. The avenues for expressing their anxieties, sorrows, and grief would have helped these carers cope better, which in turn might have contributed to their positive well-being.

The nature of the symptoms reported by the carers suggests that anxiety and depression are particularly prevalent among the carers. Both anxiety and depression are influenced by environmental circumstances, and it is not surprising that these areas reflect the difficult environment faced by many of the carers.

Correlational and Regression Findings

As indicated in Chapter 7, the correlational findings indicate a number of interesting relationships among the variables included in the study. A number of coping strategies (Problem Focused Coping, Positive Reappraisal, Seeking Social Support, Self Controlling, and Distancing/Detachment) are correlated with community setting, as are Mental Health Problems. This reflects the differences between Kerala and Scotland, which have been discussed previously.

Two coping strategies (Problem Focused Coping and Seeking Social Support) are also related with Mental Health Problems, such that higher levels of coping are associated with lower levels of Mental Health Problems. These findings are consistent with many previous formulations of the relationship between coping, social support, and mental health. Some studies have also highlighted the importance of both problem focused coping and seeking social support in reducing the impact of the stresses associated with caregiving (Billings et al, 2000; Borden, 1991; Folkman, 1997). These relationships thus seem to merit further study.

As discussed in chapter 7, quantitative data were further examined using regression analysis. In the regression analysis of a number of circumstances of the family carers in relation to mental health problems, community setting and gender made significant contributions to mental health problems, but neither the health status of the HIV-affected family member or the availability of counselling had a significant influence. These results likely reflect a number of factors. First, the finding for gender is not uncommon. Women are often found to be more vulnerable to mental health problems, whether because of social vulnerability or because of a greater likeliness to acknowledge such problems. Both factors could have been at play in the present study.

Second, the finding for community setting likely reflects the higher level of stress and the limited resources available to the carers in Kerala. Thus this finding is simply another way of viewing the differences in mental health problems between the carers in the two settings, which was discussed earlier.

The lack of a significant influence for either health status or availability of counselling may reflect the limitations of the study. With regard to health status, it is likely that there was not enough variability in this small sample to allow relationships with other variables to be detected. Since caregiving usually becomes necessary only when the HIV-affected person becomes seriously ill, it is likely that many of the participants in this study were dealing with roughly the same health status in the affected member—a fairly poor one. The lack of variability would make it very difficult to detect correlations, which are influenced both by variability and by the small sample size.

The lack of an effect for availability of counselling may also reflect limitations of the study. Virtually none of the Kerala participants, who make up the largest part of the sample in this study, had any access to supportive counselling. Thus there was little variability in this factor, and relationships could not be detected. Performing the same analysis with a larger sample of carers who have varying degrees of access to counselling services might allow a researcher to detect whether availability of counselling has any actual influence on the well-being of the carers.

The second regression analysis examined the influence of various coping strategies on the level of mental health problems in the carers. Only Problem Focused Coping was found to be a significant predictor of mental health problems. As mentioned earlier, this finding suggests that persons who use this strategy are likely to fare better than those who do not. Problem focused coping has emerged in other studies as an important strategy for dealing with stress, including that associated with providing care to family members who are ill (Borden, 1991; Folkman, 1997).

Problem focused coping involves taking direct steps to deal with the problem that is creating stress, and as such, it makes sense that carers who are able to do so would ultimately fare better in their emotional adjustment. But another way to look at the relationship is to consider that being able to take direct steps may have a beneficial effect, that is, people who see themselves as being able to take action to help the situation may experience less distress than people who feel helpless and powerless. As was noted earlier, many carers, especially those in Kerala, lacked the necessary resources to engage in problem focused coping, and thus they may have experienced a sense of powerless that contributed to mental health difficulties.

The third regression analysis reported in Chapter 7 explores the effects of problem focused coping, gender, and community setting on mental health problems. Both problem focused coping and gender proved to have significant independent effects on mental health problems; however, community setting no longer made a difference when problem focused coping was included in the analysis. This suggests that the differences between Kerala and Scotland are related to the differences in coping, and may reflect the availability of coping resources, as suggested above.

In an attempt to further understand the factors that contribute to problem focused coping, the final regression analysis reported in Chapter 7 concerned gender, education, and age as possible predictors of problem focused coping. The results of this analysis were not significant. As mentioned earlier, the lack of significant findings for this analysis may reflect the small sample size and the lack of variability in the study sample. Further exploration of these and other possible factors contributing to problem focused coping appears warranted, since this coping style seems to have beneficial effects in helping carers avoid mental health problems associated with caring.

Summary

The qualitative and quantitative findings reported in this study give an indication of the complex and difficult task faced by family carers as they deal with the needs of a family member with HIV/AIDS. The sense of obligation and commitment, the limitations on resources and supports, the pressures created by economic problems and social stigmatisation and isolation, and the changing nature of roles and tasks faced by the carers all contribute to the effectiveness of carers' efforts as well as the ultimate adjustment and health of the carers themselves. In the next section, a model is developed in an effort to further our understanding of this complex set of relationships.

Three Unifying Concepts: Struggle, Commitment and Resilience

The process of data collection and analysis provided the researcher with insights into the multiple experiences family caregivers encounter while caring for their loved one with HIV/AIDS, which are presented in the six themes discussed in Chapter 6. The researcher then began a process of critical reflection, in order to arrive at some conclusions about the meaning and significance of these six themes.

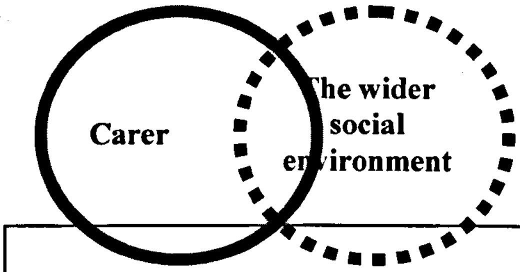
In wondering what was so unique to the experiences of these caregivers, the researcher began to explore what was beyond the visible. A picture began to emerge in the mind of the researcher—a kind of metaphor, something along the lines of a prism. When a beam of white light passes through a prism, it gets deflected as the colours of the rainbow; similarly when the six themes of the carers' experiences were reflected upon and analysed, what the researcher saw were three concepts that seemed to run through the experiences of these caregivers. Just as the multiple colours of the rainbow come together to form white light, these themes could be unified to form the concepts of struggle, commitment, and resilience. These concepts seemed to resonate strongly through the stories of the carers, and to encompass the complexity of the situation and the many difficulties encountered by the carers in their day-to-day existence.

The process of critical reflection and analysis sought to unify the varied experiences into a smaller number of concepts that could synthesize the many facets of the experience of caring for a family member with HIV/AIDS. This is a corollary of the inductive nature of the grounded theory approach. Glaser (1978) suggests that the investigator should go out in to the field without having reviewed the existing literature, with the desire not to contaminate one's effort to generate concepts from the data.

The three unifying concepts of struggle, commitment and resilience will be utilised to develop a model that attempts to explain the complex process of family caring in HIV and AIDS. An understanding of the three concepts is crucial in developing an appreciation of the model of family caring, because each concept reflects a complicated set of relationships. Each of the three unifying concepts will now be discussed, in order to provide definition and clarification of the aspects reflected in the concept.

Struggle

The first concept to be discussed is that of struggle. For the purpose of this study, the researcher believes that the concept of struggle encompasses the effort necessary to provide care and support in the context of the wider social environment. The wider social environment can be viewed in terms of the pressures and conditions that impinge upon the carer and the family, as well as the supports and resources available to assist the family as they deal with the day-to-day realities of HIV/AIDS.



Problems posed by the social environment:

Poverty
Ignorance
Lack of resources
Poor medical provision
Poor medical care
Inadequate social support
Lack of recognition
Culture of silence
Stigma
Discrimination

versus

Support provided by or within the wider community:

Extended family and friends
NGO's
Governmental supports

Figure 1. The relationship between the carer and the wider social environment

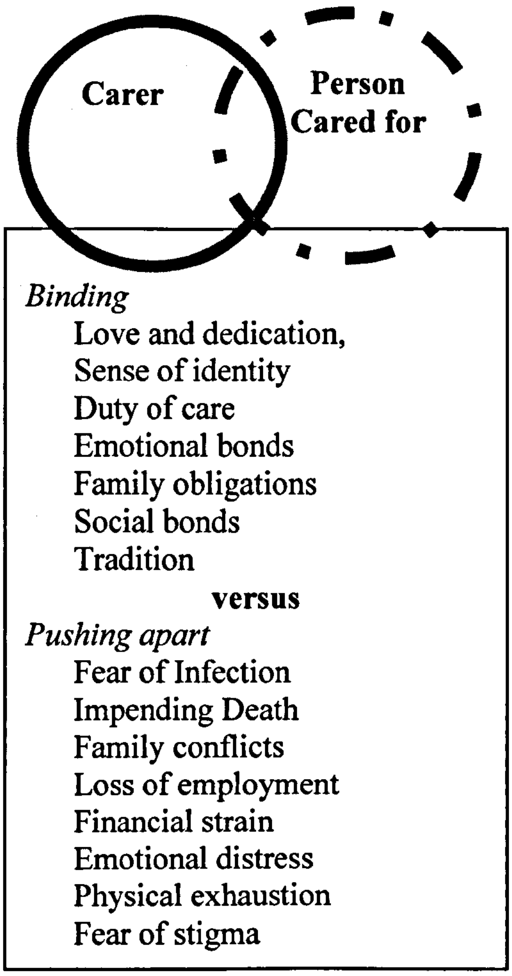
The process of care implies a relationship between the carer and the environment in which he or she must operate, and in the case of many of the carers in this study, that relationship was marked by many negative features and few positive ones. Family caring is influenced by factors such as the availability of social support and the climate of stigmatisation, as well as cultural influences that help to determine the ways that people try to cope with the burdens of caring. Because of stigmatisation and taboos, it can be seen just how great a struggle it is for so many of the carers, particularly those in Kerala, who seemed to have so little going for them.

For many of the carers, the problems and pressures were all too many, while the resources and supports were all too few, and in the case of some carers in Kerala, completely non-existent. The idea of struggle seems to capture the reality of this process, and it also reflects the exhaustion, depression, anxiety, and sense of burden reported by so many of the carers as reflected in Chapter 6. The pressures and resources, as well as the relationship between carer and the wider environment, are depicted in Figure 1.

Commitment

The next concept is drawn from the relationship between the carer and the person cared for. It reflects the sum of the forces pushing the carer and the cared-for person together, as well as the forces pushing them apart. Despite the many difficulties and pressures that the carers experience, many of them show a remarkable level of commitment to the HIV/AIDS-affected family member. The unquestioning bonds of love, duty, and compassion that led the carers to undertake and continue to bear the daily burdens demanded by caring were illustrated repeatedly in the accounts of the carers.

Caring for a family member living with HIV/AIDS often takes enormous strength and commitment. Despite the lack of support and recognition these family carers display remarkable commitment to meet the overwhelming demands of caring for their loved ones living with HIV/AIDS. They have to deal with many stressful decisions and challenges and feelings that are hard to cope with. These include anger, grief, sadness and depression, as well as the very real fear that the HIV status of the loved one will be discovered and lead to social ostracism. Caregiving in HIV/AIDS can be an emotional roller-coaster, yet even under such pressures family carers commit a great deal of their time and energy in order to be of support to their loved ones with HIV/AIDS. For many carers, making this commitment seemed to happen as a matter of course—it was simply understood as a part of their relationship with the cared-for person. For those who made a conscious choice to provide care, the reality of their sacrifices was often minimised, as they focused instead on the needs of the HIV-affected family member. Figure 2 depicts the relationship between the carer and the person cared for.



Binding

- Love and dedication,
- Sense of identity
- Duty of care
- Emotional bonds
- Family obligations
- Social bonds
- Tradition

versus

Pushing apart

- Fear of Infection
- Impending Death
- Family conflicts
- Loss of employment
- Financial strain
- Emotional distress
- Physical exhaustion
- Fear of stigma

Figure 2. The relationship between the carer and the person cared for

Resilience

The third unifying concept is that of resilience. The concept of resilience reflects the strength, capacity, and resourcefulness of the carers who found a way to go on in the face of multiple adversities—a way to go on when it seemed that they had lost everything. It is very telling that some of these carers kept on in the face of devastating obstacles, and it seemed that some of them just kept on because they had no other choice. Many of these carers simply could not afford to collapse, because then there would be no one to care for the ill person and to see to the needs of their children.

Resilience can be understood at an intuitive level, but the formal concept has deep roots in social work, although more formal research has only appeared in recent years (National Association of Social Workers, 2004). After years of focusing on pathology, social scientists have begun the task of identifying strengths, resources, and talents of individuals and families (Hawley & DeHaan, 1996; Rutter, 1987; Walsh, 1996). Resilience is variously defined as the ability to cultivate strengths (Silliman, 1994), as returning to original form/position after being turned (Valentine & Feinauer, 1993), and as compensation of one's self after experiencing hardship (Wolin & Wolin, 1993). Genero (1998) perceived resilience as a relational issue rather than as an individual attribute.

A number of authors have articulated the idea that there is more to resilience than merely surviving. According to Walsh (1996), being resilient also involves the ability "to heal from painful wounds, take charge of their lives, and go on to live fully and love well" (p. 4). Hawley and DeHaan (1996) found three common properties in the resiliency literature: hardship, buoyancy, and wellness. Further, Fraser et al (1999) suggest that "resilience literature generally affirms that the concept encompasses not merely *surviving*; but in addition it includes both *thriving* and having *benefited* from the stressor experience" (p. 136).

Other authors (Hawley & DeHaan, 1996; McCubbin & McCubbin, 1988; Walsh, 1996) have cited differences between resilience found in individuals and resilience found in families. Walsh (1996) suggested that "a focus on family resilience seeks to identify and foster key processes that enable families to cope more effectively and emerge hardier from the crisis of persistent stresses, whether from within or from without" (p. 263). Hawley & DeHaan (1996) noted that the response of the resilient family depends on a number of factors, such as the context, developmental level, and an interactive combination of both risk and protective aspects, and the family's shared outlook.

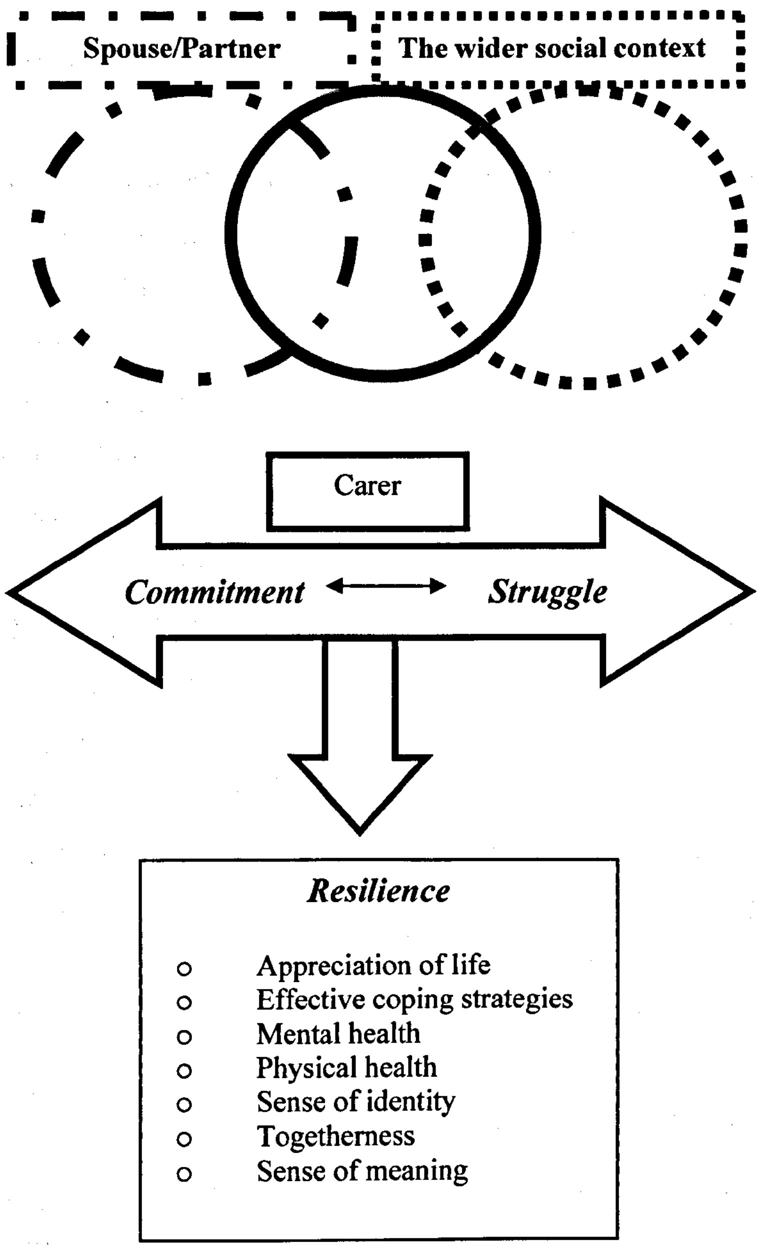


Figure 3. The concept of resilience

In the context of this study, resilience is seen as the product of the interaction between struggle and commitment. As the carers strove to manage the many duties and pressures of caring and to sustain their relationships with the HIV-affected family member, they somehow moved to a new level of commitment and a philosophical sense about the experience. A number of carers, particularly those in Scotland, spoke of the deeper sense of meaning that caring had brought to their lives. Some of the carers in Kerala also reflected on the new closeness that they felt toward the cared-for person, despite the hardships that they encountered. Figure 3 depicts the concept of resilience.

It is important however to acknowledge that this resilience was not experienced by all of the carers in the same manner or with the same degree of intensity or had similar conditions. Some reported that they were experiencing despair and hopelessness instead. It is apparent that some carers exhibited the quality of resilience to a much greater degree than others, who seemed to fall apart or deteriorate into despair and hopelessness. It might be that the capacity to form resilience is a result of certain personality characteristics, or it may reflect a difference in the environment, or perhaps both. For example, Sheena from Kerala, who had carried poison so she could kill herself if things got too bad, may not be seen as resilient as others like Gangabai who vowed to "be there" for her husband until the very end, "come what may". This may be because some of the carers who despaired had encountered an extreme number of losses at once, or perhaps were subjected to the most extreme social environment. This indeed calls for further research to see how resilience occurs and what the necessary conditions are for it.

The three unifying concepts of struggle, commitment, and resilience are utilised to develop a model that attempts to explain family caring in HIV and AIDS. An understanding of the three concepts provides a backdrop for understanding the process of family caring that is depicted in the model. The concepts of struggle, commitment, and resilience reflect the relationships between the carer and the wider social environment and between the carer and the cared-for person. They also reflect the process of resilience, whereby the carer and the cared-for person find new meaning and hope in the face of hardship.

Model of Family Caring in HIV and AIDS

Through this study, the phenomenon of family caring has emerged as a process that comprises three key elements: struggle, commitment and resilience. Various environmental and personal characteristics contribute to each of these elements, resulting in a complex pattern of interwoven influences. The diagrammatic model depicted in Figure 4 illustrates one way to conceptualize the pattern that has emerged, to explain family caregiving in the context of HIV/AIDS. This model is offered as a tool for illustrating the complex realities faced by families involved in providing care to their family member living with HIV/AIDS.

Figure 4. A model of family caring in HIV/AIDS

Through the process of reflection and critical thinking, described earlier in this chapter, the researcher synthesised the varied experiences of family carers into the unified concepts of struggle, commitment and resilience, as these seemed to resonate through the lives of the family carers across the two contexts. They portray the central theme/concept of family caring in HIV/AIDS in this study. The model depicted in Figure 4 attempts to show these concepts interacting in a dynamic, iterative way, where struggle and commitment are interlinked; that is to say each feeds into the other and vice versa. They together feed into resilience, which in turn nourishes both struggle and commitment.

The model presents the context of family caring as the backdrop of the experience of family caring. The cultural, social, and economic contexts for care reflect the resources available to the carers as well as the many pressures and problems that impinge upon their daily lives, and these are depicted in the outer circle. Family carers provide the much needed care and support to the persons living with HIV/AIDS in a context of poverty, ignorance, lack of resources, lack of recognition etc, which impact on the family caring as a whole. For many carers throughout the world, the context of care is characterized by harsh realities—limited resources, stigmatisation, and lack of recognition for their efforts.

Within the model struggle is depicted as an effort that the carers make to provide the much needed care to the family member living with HIV/AIDS amidst so many adversities. The carers are prepared to struggle, because of their love, duty, dedication, compassion, and family obligations; all of which reflect their commitment. Because of their commitment, the struggle continues. The relationship between commitment and struggle is shown by bi-directional arrows. This is shown in the middle circle, with arrows leading from struggle to commitment and backwards. The environmental and personal factors that influence each concept are listed below each concept.

Despite the challenges and limitations they encounter, family carers continue to work to provide the support needed by the HIV/AIDS-affected family member, and this is also reflected in the middle level of the model. Struggle and commitment are shown here in a dynamic relationship. Carers struggle to deal with the many adversities they face, and they continue to do so out of a sense of commitment. The sense of love, duty, dedication, compassion, and obligation that the carers feel enable them to continue the struggle, and the experience of struggle in turn deepens the sense of commitment and dedication.

The next level, resilience, reflects the ability of the carers to cope and to survive the great difficulties they face, and it is depicted in the inner circle. Again, the relationship is bi-directional. The experiences of struggle and commitment contribute to the resilience of the carers, and in turn the resilience of the carers enables them to go on. Carers who are unable to find the inner or outer resources they need to continue/go on may fall away from the caring role, while those who are resilient are able to go on and to find new meaning in their experiences and sacrifices. Struggle and commitment both help to mould resilience. Through the shared experiences of struggle and commitment, the carer and the cared-for person discover their own inner strengths, as well as the strength of their relationship. Resilience in turn nurtures both struggle and commitment. This is what gives the family carers the strength to go on, hence the centrality of this concept in the model.

Resilience is also placed at the centre of the model because of its importance. An understanding of the processes underlying resilience is extremely important in the ongoing worldwide effort to deal with the HIV/AIDS epidemic. As noted in the very beginning of this dissertation, family carers are vital contributors who provide much of the care for those afflicted with HIV/AIDS around the world. Thus, finding ways to discover resources and nurture the resilience of carers can be a key element in combating the devastation caused by the HIV/AIDS epidemic.

Conclusion

This chapter has attempted to synthesize the many findings of the study and to draw them together into a model that explains and integrates the findings. The model rests on the three key concepts of struggle, commitment, and resilience, which were arrived at via a process of reflection on the findings. These concepts, in turn were pulled together into a model of family caring, which depicts the complex relationships among the carers, the cared-for persons, and the wider social environment in which they live. The concepts of struggle and commitment are linked to an existence that finds its basis in the past, its hope in the future, and the capacity to struggle on with commitment and resilience in the present.

The model attempts to explain the process of family caring, but also to serve as a jumping-off place for further efforts to develop our knowledge about the phenomenon of family caring in HIV/AIDS, as well as explorations of ways to provide additional support and assistance to family carers around the world. In the next, and final, chapter, the implications and the possible applications of this study will be discussed, and some concluding remarks will draw the study to a close.

CHAPTER 9: CONCLUSION

Introduction

The previous chapters have presented the relevant background, the methodology, and the qualitative and quantitative findings of the study, as well as a discussion of the ways that the findings fit with the existing literature on family caring and HIV/AIDS.

This, the final chapter, draws some conclusions and points the way towards future interventions and research. The chapter begins with a brief review of the findings, and discusses the challenges and limitations of the study. The next section describes the implications of these findings for social work practice, social policy and further research. This is followed by a discussion of the contributions made by this study and concludes with some final observations.

This study highlights the harshness of the conditions faced by family carers in two contexts of development, who provide many valuable services in the world's efforts to cope with HIV/AIDS, but receive very little recognition or support for these services.

Family-based care is a critically important element of the continuum of HIV/AIDS care. It enables the delivery of humane and personalised care. In resource-scarce settings such as Kerala, where there is a paucity of community health programmes and social services, family caregiving takes on a particularly critical role. The burden of caring for loved ones living with HIV/AIDS is often overwhelming, pushing families into poverty and destitution. HIV/AIDS has and will continue to have a devastating effect in developing countries (Loewenson & Whiteside, 2001) unless a concerted effort is made to stem the tide of stigma, poverty and discrimination faced by people living with HIV/AIDS and their carers.

Review of Findings

The qualitative findings encompass six themes that were discovered through the process of analysis described previously. These themes included the many issues that accompany the advent of HIV in the carers' lives; the physical, emotional, social, and economic experiences of caring; the communication, sexual, and childrearing family dynamics that arose in caring; the unique experiences of carers who were positive themselves; the role of informal social support networks; and the contributions of formal support services.

Among the important findings included under these themes are the lack of awareness regarding HIV/AIDS of many of the carers, the problems of poverty and debt, and the many issues created by stigmatization and rejection of HIV-infected and affected persons, particularly in Kerala. Another finding highlights the carers' acceptance of the burdens of caring as part of their family duties—largely because there were no alternatives available. The carers' descriptions of their reactions to the burdens of caring indicated high levels of tiredness and exhaustion, as well as physical symptoms such as sleep difficulties, loss of appetite, and weight loss. The carers expressed many worries, feelings of loss, and a great sense of isolation, particularly in Kerala, where they often lived in fear that the HIV/AIDS status of their loved one would be revealed, resulting in social rejection and further isolation. They also expressed many economic concerns, as they tried to cope with the costs of medicines as well as the loss of income from the HIV-infected family member.

Caring engendered many changes in family relationships, both positive and negative. A number of carers spoke of communication problems, though some reported that communication improved as the family worked together to deal with the issues related to providing care. The illness of their family member brought about a number of changes in family roles, and these were often experienced as difficult and confusing for the carers. Concerns regarding sexuality and the loss of childbearing arose for many of the carers, as did concerns about the welfare of children. This concern was particularly difficult for a substantial number of carers who had children and faced the need to make arrangements for their children in the event of them becoming HIV-positive and eventually dying of AIDS.

Concerns about the availability of support were also prevalent. Many of the carers, particularly those in Kerala, felt that they had very limited access to informal social support. While the carers in Scotland reported having more informal supports available, they too found that the support they received was inadequate. The carers in Scotland did have greater access to formal support services, which were virtually nonexistent in Kerala.

The quantitative findings included some exploratory analyses that examined the coping strategies used by respondents in Kerala and Scotland as well as the mental health problems experienced by the respondents. The results indicated that the carers in Kerala and Scotland relied on decidedly different strategies when coping with the stresses related to family caring. The carers in Scotland were significantly more likely to use the strategies of problem-focused coping, positive reappraisal, seeking social support, self controlling, and distancing/detachment. The carers in Kerala were significantly more likely to use the strategy of self blame. These results suggest that the carers in Scotland had a wider array of coping strategies available to them, perhaps reflecting the greater availability of resources.

The findings for mental health problems suggest that the respondents in both settings experienced significant mental health problems, particularly symptoms suggesting depression and anxiety. The carers in Kerala reported significantly more of these problems than the carers in Scotland. Exploratory regression analyses indicated that gender, problem-focused coping, and setting were all significant predictors of mental health problems. Females, those from Kerala, and those who relied less on problem-focused coping were more likely to experience mental health problems.

Finally, when all of the findings are considered together, three synthesizing concepts emerge. These concepts—struggle, commitment and resilience—capture the essence of the experience of family caring in the two contexts and encompass the many experiences reported by the carers. The concepts also serve as key elements in the theoretical model of caring, which was presented in the previous chapter. This model attempts to depict the relationships among the concepts and to facilitate a better understanding of the complexities involved in HIV/AIDS family caring.

The present research for the first time explores the varied experiences of the carers by bringing together six themes, coping and mental health and proposing a model using the concepts of struggle, commitment and resilience all of which highlight and help to explain family caring in HIV/AIDS. The next section discusses the challenges and limitations of this study.

Challenges and Limitations of the Study

This study was intended as an exploration of a phenomenon that has received relatively little attention in the research literature, and as such it has a number of methodological limitations that should be considered. The most critical of these is the small size of the sample, particularly that in Scotland. This challenge was very difficult to overcome, because of the difficulty of accessing the family carers. Future studies in this area should strive to develop a mechanism for contacting a broader sample of family carers, so that their experiences could be studied even more thoroughly. A considerably larger sample would allow for more reliable results, particularly for the correlation and regression analyses incorporated in the study. Given the difficulties of collecting data in this population, a larger scale study would likely involve multiple investigators and greater resources for data collection.

Although the research included an attempt to examine the phenomenon of family caring in two different cultures, a larger and more representative sample of carers in each culture would be necessary in order to do cross-national comparisons. If resources permitted, a study of caring in several different cultural contexts might be particularly valuable. Again, such a research would require considerable investment of resources and would be beyond the scope of a doctoral dissertation. The current study might, however, serve as a blueprint for developing a larger cross-national study, perhaps under the aegis of international organizations involved in the study and treatment of HIV/AIDS.

Another limitation of the study concerns the instruments used to gather data. The interview method was relied on heavily, and it proved useful in uncovering information in a variety of areas. However, the use of more objective measures might have been valuable as additional means of investigating family caring. In a larger scale study, additional objective measures might be helpful in furthering the understanding of influences such as poverty, social context, and family roles. The coping and mental health measures used in this study might be further refined as well. In particular, the coping measure could be modified to more accurately measure coping strategies in the Indian population, and the mental health problems measure might be expanded in order to get a better sense of the severity of the problems reported by the respondents. The psychometric difficulties of measuring coping (Schwarzer & Schwarzer, 1996) might be considered, and a measure specific to the study of family caring in HIV/AIDS might be developed. The reliability and validity of all of the instruments could also be further explored.

Implications of the Study

The insights gained from this research suggest implications in the areas of social work practice, social policy, and further research. This section explores these implications.

Implications of the Finding for Social Work Practice

This research provides insights into the experiences of family carers in their day-to-day struggle to provide much needed care to their loved-ones with HIV/AIDS. It explores their experience of caring in two differing cultures—among carers who have differing life experiences and socio-economic backgrounds. It also examines the ways in which carers cope and the impact of the experience on their mental health. Because of the topic it examines and the population it studies, this research has important implications for social work. Social work aims to better the human condition, by focussing on meeting the needs and empowering those who are vulnerable and marginalised in society. HIV/AIDS, with its tendency to infect the most vulnerable people in society and to increase their vulnerability, presents particular challenges for the field of social work (Sidhva, 2004).

The HIV/AIDS crisis continues to unfold in a way that UNAIDS (2004a) characterizes as relentless, noting that the epidemic destroys lives and tears at the "fabric of societies", (p.13). Family carers, whose role is so central in the global response to HIV/AIDS, represent a key point for intervention and a key factor in the prognosis for communities affected by the epidemic. There is very grave danger for these communities if nothing is done to support these carers, and thus the response must be to find ways to support these carers.

UNAIDS (2004a) suggests that because the challenges posed by HIV/AIDS epidemic are daunting, "the worldwide response must outpace the epidemic itself" (p. 3). If the future is to hold hope for the millions of families living with HIV/AIDS across the world, then a response is required on a scale that has never taken place before. The sections that follow will attempt to link these findings to practical applications in the real world of family carers, with a special emphasis on direct service, education, and advocacy.

Direct services

The accounts offered by the carers in this study suggest a number of needs for direct services, particularly for the carers in Kerala, who are trying to cope with very limited resources. The most obvious need, particularly for those in Kerala, is access to adequate medical care and effective medicines. The lack of availability of antiretroviral therapy for many HIV-infected persons in the developing world has created a health care crisis that is only beginning to be addressed.

Since April 1, 2004 the Government of India has begun administering antiretroviral treatment to small numbers of people living with AIDS in the six high-prevalence states in India (Human Rights Watch, 2004; National AIDS Control Organization, 2004b). Moreover, Kerala, although not one of these six states, has announced that it would provide free antiretroviral therapy (John, 2003). Another glimmer of hope seems to emerge from the “3x5” initiative, that is, the plan by WHO and UNAIDS (UNAIDS, 2004a) to provide anti retroviral treatment to three million persons living with HIV/AIDS in the developing world by the end of 2005. If successfully implemented, this plan will bring a significant improvement to the lives of carers.

Other services are also needed. The carers in both settings mentioned exhaustion and tiredness, no doubt as a consequence of all the added duties they were performing, together with the burden of worry regarding HIV/AIDS. The need for some sort of respite service is apparent. Although some of the carers in Scotland had access to this type of service, this kind of assistance was unavailable for those in Kerala, and even the carers in Scotland felt that respite services were inadequate. Providing some mechanism whereby the carers could find time to take care of themselves and to rest would be a very valuable contribution to their efforts in caring for a family member with HIV/AIDS.

Supports for providing adequate nutrition and palliative care would also be valuable, as these issues also presented challenges for the carers. Along with these services, specific training in the proper techniques for treating wounds and other nursing interventions would be beneficial.

Supportive counselling is another fairly obvious need. Many of the carers reported symptoms of anxiety and depression, and they could likely benefit from counselling to help them cope with these difficulties and work through their feelings regarding their circumstances. Counselling could also help the carers work on solutions to the many challenges they face as carers. Support groups could also be beneficial, offering the carers the opportunity to meet with other people in circumstances similar to their own. Support groups would also help to alleviate the terrible feelings of isolation faced by many of the carers. Other efforts to enhance the social support available to the carers would also be beneficial. As this research has demonstrated, social support may be an important resource for coping with the burdens of providing care.

Many practical forms of support could also be beneficial. Assistance with finding employment would make sense in many cases where carers have lost their jobs or businesses because of the burdens and the stigmatisation of caring for an HIV-affected family member. Other types of financial supports appear necessary in many cases, as the carers exhaust their financial resources and become unable to work because of the time they devote to caring for the HIV-positive family member. Similarly, additional housing resources are needed, particularly in those cases where the cared-for and the carer are forced to leave their homes because of stigmatisation.

Relieving poverty should be a high priority. Income-generation schemes are much needed and much valued by AIDS-affected families and communities to relieve the stress of poverty (UNAIDS, 2001a). Helping families to generate income, perhaps through work done at home, should be encouraged. This aspect takes on a special significance in the light of the fact that this year, 2005 has been declared United Nation's International Year of Micro Credit. Chowdhury (2005) points out that providing poor people with micro-credit results in the creation of assets, generation of employment, economic security and empowerment.

It is also apparent that there is a need for some sort of provision for children who are affected by HIV/AIDS in a parent. Many of the carers who were parents expressed great worry about the well-being of their children. The concerns ranged from worry about lack of time for the child to worry about who would care for the child if both parents were to die of HIV/AIDS. In communities where there is great stigmatisation and rejection of those associated with HIV/AIDS, the need is particularly great.

The commitment and resilience of family carers also create implications for direct service. Carers provide valuable services that no one else in their communities can provide, yet they get no recognition or support for their contributions. Fostering recognition of their commitment and appreciation of their efforts could be a useful way to support their efforts and encourage them to go on when they are discouraged. Formal or informal support groups that help carers connect to other carers might be an invaluable service in this area. Finding ways to support family relationships and to prevent family disintegration due to stigmatisation would also be helpful. Intervention should seek to strengthen the resilience of the carers so that they maintain the capacity to continue to care for their loved ones. The strengths perspective and resilience literature suggest that social workers may learn from those people who survive and in some cases flourish in the face of oppression, illness, demoralization, and abuse. Social workers need to know what steps these natural survivors have taken, what processes they have adopted, and what resources they have used (Saleebey, 2000).

Given the broad range of needs evidenced by the carers, the need for multiple structures to provide support is evident. These include structures at the local level, which might help to combat the isolation and ostracism experienced by the carers, as well as structures that operate at the larger governmental level to provide some of the advocacy described below.

Education

This study uncovered a great need for education of the general public regarding HIV/AIDS, particularly in Kerala. It is clear that the burdens of the carers in this study were made much greater by the atmosphere of secrecy and fear of discovery in which they live. It is apparent that there are many misunderstandings about the nature of HIV infection, and many superstitions and prejudices operating among the general public that add greatly to the burden of the carers. The carers themselves also seem to need education regarding their risks of infection and the proper ways to protect themselves, as well as a need to understand that they are not to blame for the advent of HIV/AIDS into their lives.

There is a great need to address the appalling ignorance that exists in some communities in Kerala. There are a few awareness/education programmes that are geared towards the general public but little is known about their effectiveness in mitigating the effects of stigma and discrimination in relation to those infected and affected by HIV/AIDS. UNICEF (2001) points out that discrimination of people infected and affected with HIV/AIDS in India is manifested in all areas of life;

however, it is most pronounced in health care settings and in their own households. Lack of information, misconceptions, and judgemental attitudes contributed to the stigma experienced by carers in both contexts, but particularly in Kerala. Thus reducing stigma and discrimination through the dissemination of awareness and information is a priority in the context of Kerala.

Moreover, as we pass through the third decade of the HIV/AIDS epidemic, there is a great need for effective and creative strategies within communities that continue to discriminate against persons and their families infected and affected by HIV and AIDS. Social workers should be the catalysts that enable communities to embrace the inestimable values of caring for their neighbours, shunning the triple combination of ignorance, prejudice, and fear, containing it with the keys of openness, acceptance, and support (United States Agency for International Development, 2002). Additionally, social workers need to critically reflect on their own practice in relation to stigma, prejudice, and stereotypes. A powerful lesson from experience is that the battle against prejudice and stigma is never conclusively won. The association of HIV/AIDS with grim suffering, death, and behaviours that people everywhere find difficult to talk about and to accept means that the stigma of HIV/AIDS needs to be constantly challenged (UNAIDS, 2001a).

Advocacy

One of the underlying themes for many of the carers is their lack of power to make any changes in their circumstances. Poverty, stigmatization, and isolation combine to make them powerless. Many of the carers are also women, who have been traditionally relegated to positions of very limited power. This is particularly true in Kerala, where traditional values regarding the role of women are still very predominant.

It is clear that the carers could benefit from opportunities to have their voices heard and to make choices regarding their circumstances. Efforts to advocate for the carers could provide valuable assistance in these areas. Advocacy is needed to help make changes in governmental policies so that carers are recognized and supported. Social workers could also help the carers to interface with the medical care system and obtain the necessary care for the HIV-positive family member. Finally, social workers could work to protect the legal rights of carers, so that they are not deprived of jobs, family inheritance, or other resources just because of the presence of HIV/AIDS in the family.

Related to the need for advocacy is the need for greater protection of the rights of medical patients, especially the right to privacy and confidentiality. Again, this problem is the most acute in Kerala, where the lack of basic medical confidentiality poses a real threat to the well-being of HIV/AIDS patients and their families. This lack of confidentiality presents an acute problem that has the potential to undermine efforts to halt the spread of HIV by discouraging people from being tested, for fear that their test results will become public knowledge.

In both low and high-prevalence settings, HIV and AIDS hinder human development. Consequently, the epidemic's dynamics need to be explored in human development terms. Despite gains, in various parts of the world grave AIDS-related human rights violations continue to occur with depressing regularity (UNAIDS, 2004a). Article 12 of the Universal Declaration of Human Rights that states "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks" (United Nations, 1948, p.1). This study has demonstrated the many ways that these basic rights are violated when a family member is affected by HIV/AIDS.

Governments should not only adopt but implement human rights, with political commitment and leadership at every level—national, regional and local. The International Guidelines on HIV/AIDS and Human Rights (1998) call for "setting up monitoring and enforcement mechanisms to guarantee that HIV-related human rights are protected" (p.1). Experience has confirmed that protecting people's human rights decreases their vulnerability to HIV and reduces the negative impacts of HIV and AIDS. Much progress has been achieved, but the world now needs to be vigilant to prevent backsliding toward practices that are not rights-based (UNAIDS, 2004a, p.127).

In the final analysis, the act of developing political will should run in parallel with empowering carers to increase their say and to make their voices heard, so that political systems become more inclusive and participatory. The government should create an environment in which persons affected by HIV/AIDS, such as family carers, can contribute meaningfully to all aspects of the response to their needs. Loewenson and Whiteside (2001) point out that many leaders at both national and community levels still have not faced up to the threat of HIV and AIDS to the developmental agendas of their countries. They argue that political leaders continue to be a constraint in many countries and that increased political commitment and leadership at the highest level of government is required in order to bring about the necessary changes in policies and programmes.

Piot (2001) argues that human rights are central to turning the tide of the HIV/AIDS epidemic and that they need to be at the forefront of the response. He argues, "simply put, AIDS is one of the most serious human rights challenges of our time. It has brought in its wake widespread discrimination and other human abuses, set back the right to development, and in the hardest-hit countries it threatens the very essence of human security" (p.1). Moreover he suggests that the success of any intervention in the HIV/AIDS pandemic depends upon the promotion and protection of human rights. He adds that respect for human rights is intricately linked to reducing vulnerability to HIV/AIDS epidemic. The impact of HIV/AIDS on the infected and affected persons is exacerbated when human rights are violated. Family carers of persons with HIV/AIDS suffer double jeopardy—not only do they have to deal with serious health conditions in their loved ones but they also have to deal with loss of basic human rights, such as right to confidentiality as elucidated in Sheena's account in Chapter 6. Heyzer (2001) asserts that, given the imminent dangers and dimensions of the pandemic, it is crucial to recognise the importance of upholding the human rights of family carers in "turning the tide" of the pandemic (p.i). Safeguarding human rights is an essential part of responding effectively to the epidemic at individual, national, and global levels (UNAIDS, 2004a).

Finally, there is a need for a commitment to advocacy as a means to develop policies and programmes for family carers of persons living with HIV/AIDS. Policies and programmes need to address the underlying economic, social, and cultural factors that increase carers' vulnerability, because HIV/AIDS strikes hardest where human rights are least protected. Stigma undermines the dignity and human rights of carers and causes untold hardship.

The community is the frontline in the fight against HIV/AIDS. It is vital to mobilise communities to play an essential role in initiating awareness, education, and caregiving services. Once communities recognise that they have the power to respond to the HIV/AIDS epidemic, they are in a position to reduce stigma and provide care for families.

Implications of the Findings for Social Policy

This study also has a number of implications for social policy. As the HIV/AIDS epidemic strikes at the very heart of the family, there is a "moral imperative" (p.2) to ensure that the needs of family carers are brought to the forefront of policies and programmes that address their needs (UNAIDS, 2001b). Thus, it is important to design programs and policies that enhance and reinforce the traditional coping responses of extended families and their communities. Policies that recognize the contributions of family carers and help to meet their needs should be implemented at local and national levels. These policies could support efforts to deliver needed medical care and drugs, to foster education and understanding of HIV among the general public, and to provide a system of supports for family carers.

Moreover, it is crucial that all policies for family carers should keep the issues of stigma, discrimination and other ethical and human rights issues in the forefront. Governmental and non-governmental organisations should develop and initiate policies and programmes that address the psychosocial needs of the carers, in an attempt to reduce the stigma and discrimination experienced by families affected by HIV/AIDS. The Population Council (2004) suggests that stigmatization of people living with HIV/AIDS and their families in Kerala remains severe and poses a key barrier to care and support. Hence critical attention is required to address this problem.

Because of the broad scope of the problem of HIV/AIDS, particularly in developing countries, it will be essential to involve governmental entities that can provide support and foster change at a broader level. As discussed in chapter 3 there have been such policy developments in the UK that recognise the contribution made by carers. The Carers (Recognition and Services) Act 1995 (Her Majesty's Stationery Office, 1995) has paved the way for acknowledging the role the carers play and an understanding of their needs (Qureshi et al, 2003) and has raised the profile of unpaid family caring. Brechin et al, (2003) argue that referring to these services as *care* and making care a focus of government policy "shines a spotlight"(p.160) on family caring. However, in the context of Kerala, there does not seem to be any policy level discussion of similar provisions that would guarantee the recognition that these carers deserve. The Carers (Recognition and Services) Act 1995 provides a good example for policy makers in Kerala to draw upon. Family caregivers in Kerala should be recognised as a distinct resource in caring for persons living with HIV/AIDS. There is a need for a framework/policy that provides guidance and regulations for financial and practical support. It is important, however, to reiterate the fact that Kerala does not have a welfare state or any form of statutory social work practice. Thus, it is important to acknowledge that it may be a while before such policies are developed.

A significant observation that emerged from the carers in Kerala was the fact that many carers, who were the wives of HIV-positive husbands, were HIV-negative themselves. Any policies and intervention designed to support family carers of persons with HIV/AIDS should promote HIV prevention. This would include creating awareness about potentially risky behaviours and identifying strategies for reducing risk. Practical strategies to support risk avoidance should be implemented, such as promoting couple counselling, using personal testimony to change behaviour, promoting the use of condoms to prevent HIV transmission, and empowering carers to communicate with their partners (Rutenberg et al, 2002).

Gender inequality is driving the epidemic in India, as in many other parts of the world (UNAIDS, 2004b), making the need for gender sensitive policies and programmes for family carers necessary. Policymakers in the context of Kerala should be increasingly concerned about the welfare of the female spouses who are particularly affected by the morbidity and mortality of prime-aged male spouses brought on by the AIDS epidemic.

Finally, policies need to address the issues of poverty and financial support that are crucial issues in the lives of family carers (Howard et al., 2001). Barnett and Blaikie (1992) argue that it is of utmost importance that the coping capacity of households and communities is closely examined, so that policies and programs that are considered encourage support to carers to build their coping capacities.

In conclusion, strategies are required that place family carers at the forefront of policy formation and implementation. A critical change in the awareness of the international community about the centrality of the family carers' role is required.

Implications of the Findings for Further Research

One of the most important functions of an exploratory study is to generate ideas for further research in an area. This study has yielded a number of interesting findings that suggest possibilities for further research. These studies can add to the body of knowledge regarding family caring, as well as the research on coping and mental health.

With regard to family caring, a number of studies could be done to explore the factors that influence family carers. The influences of poverty and stigmatization on family caring could be explored further, as could various strategies to reduce the impact of these problems.

Support systems for family carers could also be investigated further, particularly the supports offered by extended family. A number of studies could be done on the changes in family roles that are brought about by the circumstances of family caring, and the impact of these role changes on family members could also be studied. The problems of raising children in the context of family caring could be explored.

A number of possible interventions could also be examined as ways to help ease the burdens experienced by family carers. These might include services such as counselling or support groups, as well as other interventions designed to improve communication and role functioning in the family care situation. The interventions should be evaluated to determine the most cost-effective way to provide support for family carers, particularly in communities where the resources are limited.

This study has also uncovered a number of positive aspects of family caring, which should also be studied. The capacity of the family carers for commitment was a particularly striking finding of this study. It would be valuable to study this phenomenon further, in order to understand how the carers come to make such a commitment. Studies of interventions that help to foster commitment and support would also be useful. Although this study focuses on the aspects of adversities and struggles in the lives of the family carers, it may be interesting for future studies to focus on the positive aspects of caring and aspects of reciprocity and interdependence which characterise many caring relationships (Stalker, 2003).

Similarly, the surprising strength and resilience of many of the carers suggests other avenues for study. What sort of personal qualities contribute to the resilience of family carers? Can things be done to help support carers who are less resilient? Are there qualities of the relationship between the carers and their HIV-positive family members that can help to foster resilience? Grant (2003) suggests that if families are to be supported or to be empowered, then professionals will need to be knowledgeable about what strengths families have, so that these can be recognized, learned from, and reinforced. Moreover, it could be viewed that an assessment of these resilient qualities should be a foundation for intervention in supporting families.

With regard to coping and mental health, the relationships suggested by the current study could be further explored with a larger sample size and a more varied population. Differences in coping strategies among carers in different settings could be further explored. Also, the roles of poverty and stigmatization as influences on coping style could be investigated. In particular, studies could examine the influence that these factors have on the ability of the carers to engage in problem-focused coping. Similar investigations could examine the ways in which the social environment of the carers influences their coping efforts, particularly seeking social support as a coping mechanism. The roles of religious beliefs, such as the belief in karma, could also be investigated further.

With regard to mental health, the influences of the stress of caring could be further investigated. It would be useful to track changes in the mental health functioning of carers over time, to learn how changes in the condition of the HIV-infected family member influence the mental health functioning of the carer. Strategies for treating the mental health problems of carers, such as depression and anxiety, could be investigated as well. It is important that research on the relationship between coping and mental health of family caregivers should not only include the gender element but should specifically focus on it, given the female face of family caregivers of persons with HIV/AIDS.

Caring for caregivers is not only a humanitarian imperative; it is a social and economic necessity in many parts of the world. More systematic studies of stress among carers are needed, in particular studies of the different strategies used to cope with stress, how well they work, what they cost, and their effects on the quality of care as well as on the morale of carers. There is also a need to study the effect of carers being HIV-positive themselves, in addition to being poor and powerless as well—suffering from the so-called double jeopardy.

Given the many gaps in knowledge in relation to mental health and coping of family carers in the field of HIV/AIDS, it would be valuable to conduct longitudinal research that looks into the different aspects of these areas in both developed and developing world context. While each context has special needs, problems and challenges, there are some fairly consistent principles for enhancing mental health and coping. It is critical to study family carers in the field of HIV/AIDS whose coping and mental health reflect success if these experiences are to be replicated.

Additionally, it would be useful to conduct studies that incorporate similar objectives and methodologies to the present study. These could be conducted in multiple sites with a larger sample, in order to help establish the validity and reliability of the findings of the present study. The resulting information could then be generalised to inform a theory of family caring in HIV/AIDS.

The next section discusses the contribution of this study to the existing body of knowledge and social work practice.

Contributions of the Study

The uniqueness of the study stems from its design, which included a cross-national dimension, wherein the experiences of family carers from two contexts of development were explored from the carer's own perspective. The aim was to extend the understanding of family caring in the HIV/AIDS epidemic by examining it in the two contexts.

Moreover, the study utilised both qualitative and quantitative methods, with the aim of developing a deeper understanding of the challenges experienced by family carers, the strategies utilised by them to cope with these challenges, and the impact that the experiences have on their mental health and general well-being. The grounded theory approach used as the methodological basis of the research provided an exploratory perspective, which not only enabled exploration of the existing questions, but also enabled discovery of new ones. Thus the qualitative element of this study was able to generate new ideas and new areas for research and raise new questions that flowed out of the lived experiences of family carers of persons living with HIV/AIDS. The inclusion of the quantitative aspect helped to link the study to other quantitative data on coping and mental health, and it led to insights vis-à-vis relationships among these phenomena in the context of family caring for HIV/AIDS. The contribution of this research lies in the combination of the areas that it sought to explore—experiences, coping, and mental health. As suggested earlier, this study is unique because it combines these three aspects in its focus on the lives of family carers of persons living with HIV/AIDS.

Finally, this study develops a theoretical model that aims to explain family caring in HIV/AIDS. The model examines the concepts of struggle, commitment, and resilience that underpinned the experiences of the family carers in this study. It provides a framework that enables professionals working in this field to intervene meaningfully with family carers of HIV-positive persons and contribute effectively towards ameliorating the suffering that is rooted in the socio-cultural, economic, and political realities of the HIV/AIDS epidemic.

A meaningful contribution of this research is the fact that it has made the experiences of family carers of persons living with HIV/AIDS more visible, albeit in a limited way. It is hoped that hearing the voices of these family carers would have an impact on those responsible for developing programmes and policies that aim to address and recognize the contribution made by them.

Some Closing Remarks

This study was undertaken at a time of great urgency. As the HIV/AIDS epidemic widens its grip on the humanity, poverty and lack of appropriate medical care has necessitated a shift in the paradigm of care provision, especially in the developing world. While family-based care is often the only care and support available to persons with HIV/AIDS in developing countries, there has been a steady transition of care from hospital to community settings in developed countries as well. Understanding the needs and voices of family carers is vital to inform policies and programmes designed to support the provision of this care in the community. When carers are treated with both knowledge and compassion it makes the difference between misery and isolation, and affords the chance to provide meaningful support in an atmosphere of dignity and respect.

The voices of family carers of those living with HIV/AIDS are crucial in their struggle against the epidemic, irrespective of their context. Mellors (2003) asserts that if the last two decades of fighting the epidemic has taught us anything, then it is that the fight against HIV/AIDS needs to include the voices and perspectives of those affected by it. There are an ever-increasing number of voices from the community calling for additional and enhanced attention to the needs of carers in their homes and stressing the importance of facilitating and enabling this care and not taking it for granted. It will be vital for these voices to be heard at both national and international policy levels, so that action on increasing the "care agenda" proceeds swiftly. This agenda needs attention even in the light of the growing availability and ease of access of HIV/AIDS medication in poorer countries.

HIV/AIDS has a profound and wide ranging impact on the lives of individuals. But for every individual who contracts the virus, there are families and communities that are affected. However, HIV/AIDS is not a problem that should be the concern of only those directly affected. As we pass through the third decade of the epidemic, effective and creative strategies that address the needs of family carers of persons living with HIV/AIDS are more critical than ever. We are all affected by the loss of lives and resources and possibilities, and how we choose to reach out and respond—society's shared degree of vigilance, compassion and resolve—are all measures of our collective humanity (USAID, 2002).

The HIV/AIDS epidemic impinges intensely on every aspect of the lives of carers. Thus, the effort should be geared towards developing a comprehensive service that would provide the basic needs of life, job opportunities, and a guarantee of human rights. USAID (2002) suggests that there is a need for developing a comprehensive package of care for the carers. This should reflect a broad spectrum of interventions that provides a wide range of services including counselling, supportive care, ethical treatment, and guarantee of human rights.

The accounts of the carers in Kerala and Scotland presented in this research provide a glimpse into the lives of family carers of persons with HIV/AIDS, across two contexts of development. Across both the contexts, it was evident that family carers cared compassionately and genuinely for their affected family members, despite the overarching stigma and discrimination. Although this research gives but only a snapshot of the carers' accounts, their voices are significant and ones that need to be heard, in the hope that their lives are made visible and better understood and that their struggles are made easier.

The study has described the pathos of family carers affected by the HIV/AIDS epidemic. In both the contexts of the study, what stood out was the need for these carers to be supported as well as empowered, equipped and enabled to meet the enormous demands which are being made on them. While some efforts are being made to relieve the burden of HIV/AIDS care on family carers in the West and in Africa, much more needs to be done in the context of India to enable individuals and families to survive in a world transformed by AIDS (Ogden et al, 2004).

UNAIDS (2004a) points out that the HIV/AIDS epidemic is an extraordinary sort of crisis, and that to stand any chance of effectively responding to the epidemic we have to treat it as both an emergency and a long-term development issue. This means resisting the temptation to accept the inevitability of AIDS as just another of the world's many problems. The AIDS epidemic is exceptional; it requires an exceptional response that remains flexible, creative, energetic and vigilant.

Clearly this study evinces the contribution of women as family carers in both contexts. It is crucial that any intervention to address the needs of family carers recognizes this fact. One of the most important contributions that can be made to combating the epidemic is to guarantee the participation of women (both infected and affected) at all levels (UNIFEM 2001).

What strikes most is the commitment the family carers in this study display and the tenacity with which they strive in the hope that their little contribution can somehow minimise the hardship and distress faced by their family member living with HIV/AIDS. Gangabai's poignant words "*I will be by his side, until the end, no matter what it does to me*" echo the tribute Sherr (2000) pays to the remarkable contributions of caregivers who are always there until the very end. In the struggle amidst poverty, stigma and discrimination, what springs up is a ray of hope, a sense of confidence, as Sheena invoked:

> *"I hope one day I will be able to prove to the world that I was right in caring for my husband ... I hope the world will accept HIV with more compassion ... as just another illness ..."*

In closing she recited a verse in Sanskrit from the Upanishads:

Asatoma Sat Gamaya
Tamasoma Jyotir Gamaya
Mrityorma Anritam Gamaya

It translates as:

From untruth, lead me unto truth,
From darkness lead me unto light,
From death lead me unto life everlasting.

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APPENDIX A: LETTER OF INFORMATION

Dear Respondent

I am a student from the Department of Social Work, University of Strathclyde, Glasgow, UK, doing a *PhD in Social* Work. I am presently carrying out the fieldwork for my dissertation - **"Family Caring in HIV/AIDS: Experiences, Coping and Mental Health".**

Through this study, I aim to develop an understanding of the varied aspects of family caring in HIV/AIDS, and how the process of caring affects the coping and mental health of the carers.

The areas I would like to explore with you include: caregiving experiences; the nature of support available to carers; how carers cope with caregiving and finally how it impinges on their mental health. Sharing your experiences will give a deeper insight and awareness to other carers like yourself and professionals in the field of HIV/AIDS. I will be interviewing carers from Kerala and Scotland. Conducting the research in two different parts of the world will extend the understanding of family caregiving in different communities.

The interview will consist of one session of approximately two and a half hours that will include an in-depth interview and two questionnaires. The interview will be tape recorded to ensure an accurate record of your words. I would like to complete the questionnaires after the interview, but in case of time constraints, these can be completed at a later session or by you at home and mailed to me at your earliest. A pre-paid addressed envelope will be attached for your convenience.

I would like to assure you that you are not obliged to answer any questions that you do not want to or which make you feel uncomfortable. Moreover, I would also like to assure you that any information that is shared with me will remain confidential. However, anonymous transcripts of the interviews will be shared for academic purposes with my supervisors; and the final printed report with anonymous quotes will be accessible to the public.

I would be happy if you would agree to participate and share your experiences with me. I thank you for your time and effort.

Sincerely

George Palattiyil
Department of Social Work, University of Strathclyde,
Jordanhill Campus, 76, Southbrae Drive, Glasgow G13 1PP

APPENDIX B: LETTER OF INFORMED CONSENT

This is to certify that I, (print name) agree to participate as a respondent in the research on "**Family Caring in HIV/AIDS: Experiences, Coping and Mental Health**". I am happy to be interviewed and for these interviews to be taped. I understand that the tapes and the questionnaires will not be made available to anyone other than the researcher. I understand that the information I share with him may be published anonymously.

I understand that participation is voluntary and that I am free to withdraw from the interview at any time. I am also free to deny answering any specific question I choose to. I have been given the opportunity to ask questions, and all these have been answered to my satisfaction.

Signature of Respondent

Date

APPENDIX C: INTERVIEW GUIDE

Background Information about the Carer/Respondent

Name (optional)

Age: 15-20 21-25 26-30 31-35 36-40 41-50 51-60

Sex: Male Female

Marital Status: Married Single Divorced Separated Widowed

Education: Primary Secondary Higher Secondary Degree PG

Occupation ………………………………………………………………………….

Relationship to the cared-for: Husband wife partner mother/dad/parents/child

Household composition ……………………………………………………………

Area of residence: village town city

Information about the Cared-for

Name (optional)

Age: 15-20 21-25 26-30 31-35 36-40 41-50 51-60

Sex: Male Female

Marital Status: Married Single Divorced Separated Widowed

Education: Primary Secondary Higher Secondary Degree PG

Occupation ………………………………………………………………………….

Present health status____

Health status in the past______________________________________

Is working currently ____

Is on medication____

Access to Counselling______________________________________

1. Learning of the test and diagnosis:

How and when did you learn that he/she was HIV positive – discuss.
What was your reaction/response - discuss.

2. As a carer your knowledge of HIV/AIDS:

Before learning of his/her illness, did you know anything about HIV/AIDS?
Current knowledge about HIV/AIDS.
Have you tried to gain further information from any other source?
Where did you get the information from: - other members in the family, partner; counsellor; GP/doctor; media; any other.
Do you feel you have adequate information now?
Different ways of reasoning out the occurrence of HIV in the family: - destiny/karma; punishment; self-blame; just like any other medical problem; blame somebody else for bringing the disease into the family.
Do you know of someone else having the illness?
Are you involved in any group meeting related to his illness - discuss.
Do you think this is helping you - in what way – explore.

3. Carer's initial response to positive status of the family member:

What was your initial reaction to knowing that he/she has HIV/AIDS?
Did you understand the implication of the status?
What did you feel about knowing that he/she has HIV/AIDS?
What explanation did he/she offer for contracting the virus? What was your reaction to it?
What is your attitude to him/her now (feel angry, wronged, cheated, feel it is fate etc.).
How would you describe your relationship with him now (normal as before, more loving and considerate, has deteriorated, not talking terms.
Were you asked to go for HIV testing – discuss.
If tested negative, do you fear of self infection.
Have you shared this information with your parents, siblings, anybody else – discuss.
What was their reaction – discuss.
Do you find that the in-laws treat you differently as compared to your husband – elaborate (in the case of wife).

4. Becoming a Carer:

How did you come to become a carer?
Did you realise that you might become involved in looking after him/her.
What did you think this might involve.
Would you say caring for him/her was something just happened or a conscious decision.
Did you have to make any changes to accommodate this role?

5. The Caring Role:

How would you describe your care for him/her: Practical help, emotional support, any other support - discuss.
If physical care is needed, describe the kind of care provided.
Is the need for hospitalisation or hospice being felt now?
Could you describe a 'typical day'?

6. Physical Aspects of Caring:

What changes, if any, have you had to make in your lifestyle due to caring for him/her.
Do you feel restricted in any way owing to the additional burden of caregiving: Social activities; visiting family/relatives; going on a holiday; any other – discuss.
How far do you think he/she is dependent on you for his/her daily chores – discuss.
Do you feel tired, bored, exhausted – discuss the physical burden of caregiving.
Do you have to juggle work and other responsibilities in conjunction with caregiving – discuss.
Do you think your workload has changed at all since caring for him/her?
Health of the carer (awareness of own health, worries regarding HIV, fear of being infected).
Has there been any disruption to your normal daily life.

7. Emotional Experience as a Carer:

How has his/her positive status affected you or other members in your family in terms of emotions (viz. shock, fear, panic, stress, confusion, anger, bitterness, anxiety, guilt, resentment, depression, hopelessness, helplessness, dispiritedness, meaninglessness, embarrassment, loss of pride, self esteem, privacy and personal control; loss of self image, loss of family prestige, concern about one's own health, emotional pain and anticipated grief over the impending death).
What was the impact on the household atmosphere (depressed, normal, no change, demoralised etc.).
Are you worried that the positive status will be somehow revealed and there will be adverse repercussions.
Do you feel you will be discriminated more than him, if you were to survive him?
Does the family feel that its reputation in the community has been damaged?
Do you or your family experience stress/anxiety over maintaining secrecy.

8. Social Aspects of Caring:

To what extent do you feel comfortable talking to immediate family about his/her illness – discuss.
To what extent do you feel comfortable talking to friends about his/her illness – discuss.
Do people act differently in your presence since they know that he is ill – explore.
Do other members in the family create any problems for you/isolate you.
Do they blame you saying you have dishonoured the family name and prestige?

Are you allowed to attend family functions?
Are you allowed to visit your relatives / relatives to visit you?
What is the response from the community/friends?
Do you feel isolated by the community in which you live – discuss.

  Opposition to attend social functions like marriages.
  Opposition to use public facilities like common well, public telephone, toilets.
  Pressure to change location of residence.
  Denial of job opportunities for the family.
  Complete ostracism from the community.
  Any other - discuss.

Are they (community people) afraid of being infected through maintaining social contacts with you/him?
Do they visit you at your home / do you visit theirs.
Do you become the centre of scorn and shame in your neighbourhoods?
Do your friends find it difficult to continue to interact with you?
Do you feel hesitant to:

  Attend social gatherings and family functions
  To mix around with friends
  To visit your relatives
  To visit your neighbours and friends
  To visit places of worship

Fear of stigma, discrimination- discuss.

9. Financial Aspect of Caring:

How are you managing financially since the problem of HIV/AIDS began.
Does his/her medical needs go unattended due to lack of funds?
How has HIV/AIDS in the family affected your income: Loss of self/partner's job; Increase in medical expense; any other- discuss.
Apart from being a carer, are you also working?
When did you start work?
The reason for the carer to take up work: To meet the present economic/medical needs; to make a saving for the future; to keep the mind occupied; to prepare oneself to be independent; Any other – discuss.
Presence of financial strain in the family due to: Increase in medical expenses; Loss of job for the positive person; Travel expenses to clinic/counselling centre; Purchasing additional support/care; Any other – discuss.
Possibilities of reducing such strain in the future: Using the past savings; Putting off paying the bills; Cutting expenses to the very minimum; Seeking help from family/relative; Seeking public assistance; Contacting NGOs/voluntary donors; Any other - discuss.

10. Matters relating to fear of Infection and Reproduction:

As a carer, do you fear you will be infected – discuss this in the context of carer being a sexual partner.
What kinds of fears do you have while caring for him/her?

Do you think there is a possibility of infection to other members in the family?
Is this fear verbalised among other members in the family.
Are preventive measures being taken (use of protective measures, isolating the person, separating personal items, eating pattern, etc.).
What is your perception of how you can be infected from you partner – explore.
Do you feel a sense of betrayal/ resentment?
Do you find it difficult to express your emotions and feelings to him?
Are you able to discuss your feelings related to intimacy and sexuality in an open manner with your partner?
Have you had any recent pregnancy – discuss this in the context of vertical transmission?
How do you describe your feelings towards each other now (supportive of each other, blaming one another).

11. Matters Relating to Children:

Do you have/are you planning to have any children - discuss.
Do the children know about their parent's present status?
How did they come to know of the status - discuss.
Difficulties in explaining the status to the children - discuss
Their reaction :- Fear of losing the parent; Fear of approaching the parent; Shock; Anxiety; Social withdrawal; Any other – discuss.
Partner's illness affecting the child's education: - Stopped going to school; frequent absenteeism; fall in grades; any other.
Do the children face any problems from the community/friends/peers etc.
Do you feel you are able to give enough time for the children?
Do you feel you need help/support with respect to children - discuss.

12. Informal Support Network:

Apart from the members living in your house, who are the regular visitors to your house (relatives, married children, friends, colleagues, neighbours).
Who from among these is perceived as a source of support?
Has the positive diagnosis shared with any of these persons; their response – discuss.
The kind of support being sought/given - discuss.
Do these people readily provide support or do they feel compelled.
Do you feel the positions/status of the family is being compromised when seeking support from these members?
Do you wish you could avoid seeking help from these members?
Are you a member of any community group – community welfare group, religious organisation, peer group, ethnic group etc.
Do you seek help/support from these groups for the current situation – discuss.
In overall terms, do you feel you have adequate social support network to fall back upon in times of need/crisis.

13. Formal Support System:

Can we now discuss the institutional/formal supports that are available (hospital/doctors, community clinic, family doctor, social worker(s), counsellors, community psychiatric nurses, specialised HIV/AIDS clinic).
Do you seek any medical treatment for you or for him currently?
If you do not, can you give any reasons: Medical treatment is very expensive; don't have enough time; will miss a day's wage if I go to a doctor with him/her; Any other – discuss.
What stage of his illness, did you seek medical help?
What kind of medical help/treatment did you seek for him: Herbal; Homeopathic; Allopathic; Alternative Medicine?
If allopathic treatment was sought where did you seek this from: Government hospital/dispensary; Infectious disease hospital; Private clinic; Private hospital; Voluntary organisation clinic; others (specify).
What is the reason for choice of this particular health centre: Specialised treatment available; Free or concession treatment available; Good treatment / nursing care; the doctor is known to us; near at home; feel assured that they will keep the information confidential; others - discuss.
What has been your experience with the medical staff - discuss.
Do you seek help from any social work agencies to arrange any care, home help, respite care, social security benefits etc.
What was your experience - discuss.

With this, I have come to the end of the interview. Many thanks for sharing your thoughts, emotions, feelings and experiences with me.

APPENDIX D: WAYS OF COPING SCALE

This Questionnaire is used to find out how individuals handle difficult situations in their lives. The list provides some of the commonly used ways of handling stress and reducing distress. I would like you to read each item in the list carefully and circle **'Yes'** if you use the method often or frequently and circle **'No'** if you use the method infrequently or not at all. Please do not omit any item, if there are any particular methods or things that you do in times of stress that are not included in the list, kindly write them in the space provided with each method.

1. Just concentrated on what I had to do next – the next step	Yes	No
2. I tried to analyse the problem in order to understand it better	Yes	No
3. Turned to work or substitute activity to take my mind off things	Yes	No
4. I felt that time would make a difference/remedy things – the only thing to do was to wait	Yes	No
5. Bargained or compromised to get something positive from the situation	Yes	No
6. I did something which I didn't think would work, but at least I was doing something	Yes	No
7. I compared myself with others and felt that I was better off	Yes	No
8. Talked to someone to find out more about the situation	Yes	No
9. Criticized/lectured/blamed myself	Yes	No
10. Tried not to burn my bridges, but leave things open somewhat	Yes	No
11. Hoped a miracle would happen	Yes	No
12. Went along with fate; sometimes I just have bad luck	Yes	No
13. Went on as if nothing had happened	Yes	No
14. I tried to keep my feelings to myself	Yes	No
15. Looked for the silver lining, so to speak; tried to look on the bright side of things	Yes	No
16. Slept more than usual to avoid the problem	Yes	No
17. I expressed anger to the person(s) who caused the problem	Yes	No

18. Accepted sympathy and understanding from someone	Yes	No
19. I told myself things that helped me to feel better	Yes	No
20. I was inspired to do something creative	Yes	No
21. Tried to forget about the whole thing	Yes	No
22. I got professional help	Yes	No
23. Changed or grew as a person in a good way	Yes	No
24. I waited to see what would happen before doing anything	Yes	No
25. Sought reassurance and emotional support from family members	Yes	No
26. I made a plan of action and followed it	Yes	No
27. I accepted the next best thing to what I wanted	Yes	No
28. I let my feelings out somehow	Yes	No
29. Realized I brought the problem on myself	Yes	No
30. I came out of the experience better than when I went in	Yes	No
31. Talked to someone who could do something concrete about the problem	Yes	No
32. Got away from it for a while; tried to rest or take a vacation	Yes	No
33. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc	Yes	No
34. Took a big chance or did something very risky	Yes	No
35. I tried not to act too hastily or follow my first hunch	Yes	No
36. Found new faith	Yes	No
37. Maintained my pride and kept a stiff upper lip	Yes	No
38. Rediscovered what is important in life	Yes	No
39. Changed something so things would turn out all right	Yes	No
40. Avoided being with people in general	Yes	No

41. Didn't let it get to me; refused to think too much about it	Yes	No
42. I asked a relative or friend I respected for advice	Yes	No
43. Kept others from knowing how bad things were	Yes	No
44. Made light of the situation; refused to get too serious about it	Yes	No
45. Talked to someone about how I was feeling	Yes	No
46. Stood my ground and fought for what I wanted	Yes	No
47. Took it out on other people	Yes	No
48. Drew on my past experiences; I was in a similar situation before	Yes	No
49. I knew what had to be done, so I doubled my efforts to make things work	Yes	No
50. Refused to believe that it had happened	Yes	No
51. I made a promise to myself that things would be different next time	Yes	No
52. Came up with a couple of different solutions to the problem	Yes	No
53. Accepted it, since nothing could be done	Yes	No
54. I tried to keep my feelings from interfering with other things too much	Yes	No
55. Wished that I could change what had happened or how I felt	Yes	No
56. I changed something about myself	Yes	No
57. I daydreamed/imagined a better time/place than the one I was in	Yes	No
58. Wished that the situation would go away/somehow be over with	Yes	No
59. Had fantasies or wishes about how things might turn out	Yes	No
60. I prayed	Yes	No
61. I prepared myself for the worst	Yes	No
62. I went over in my mind what I would say or do	Yes	No
63. I thought about how a person I admire would handle this situation and used that as a model	Yes	No

64. I tried to see things from the other person's point of view	Yes	No
65. I reminded myself how much worse things could be	Yes	No
66. I jogged or exercised	Yes	No
67. Anticipated probable outcomes and mentally rehearsed them	Yes	No
68. Visited places of worship, went on a pilgrimage	Yes	No
69. Sought assurance and support from friends	Yes	No
70. Retreated to a quiet, favourite spot to think things over	Yes	No
71. I attended prayer groups	Yes	No
72. I went for long walks	Yes	No
73. I wore a lucky charm or amulet	Yes	No
74. Consulted a faith healer	Yes	No
75. Attended religious/philosophical discourses and talks	Yes	No
76. Started practising yoga/meditation	Yes	No
77. Consulted an astrologer	Yes	No
78. Paced up an down thinking about the problem	Yes	No
79. I spent time in the company of children	Yes	No
80. Wrote short stories, poetry etc.	Yes	No
81. Thought I have a purpose or meaning in my pain/suffering	Yes	No
82. Read novels, magazines etc, much more than usual	Yes	No
83. Read books on philosophy or religion	Yes	No
84. Became a member of group, club or organisation, if already a member, attended group activities	Yes	No
85. Felt that other people are responsible for what has happened	Yes	No

APPENDIX E: SELF-REPORT QUESTIONNAIRE (SRQ)

This Questionnaire is used to find out how individuals feel emotionally and psychologically in their daily lives. I would like you to read each item in the list carefully and circle **'Yes'** if you experienced that item and circle **'No'** if you did not experience it. The notes in italics given under each question contain information to understand the question better.

1. Do you often have headaches? yes/no

The interviewer will mark down "yes" if the informants say that in the last 30 days they have suffered from frequent headaches. It is important to insist o n how frequent they are. If the informants say it is occasional or when hey have the flu, do not rate it as positive. They must have felt these pains at least two times a week.

2. Is your appetite poor? yes/no

The interviewer will rate "yes" if the informants say they have had a poor appetite in the last 30 days. If this is not the case the interviewer will rate "no". The amount of food available or the quality of food is not implied by this question.

3. Do you sleep badly? yes/no

If the informants answer "yes", the interviewer will ask what these difficulties seem to be and will write this down. It could be that informants have problems falling asleep or maintaining sleep. They might also complain of poor quality sleep. When the informants give reasons such as "I don't sleep well because my bed is uncomfortable" the interviewer will rate this question as "no".

4. Are you easily frightened? yes/no

The interviewer will mark down "yes" when the informants say that they are easily frightened and this constitutes a behavioural pattern recognised by other people. The informants may say, "I always feel on edge".

5. Do your hands shake? yes/no

The interviewer should rate "yes" when the informants say their hands tremble. The interviewer may ask the patients to show their hands, just how it is that the hands tremble. This item is referring to an anxiety disorder; any trembling caused by a physical impairment should be rated as "no".

6. Do you feel nervous, tense or worried? yes/no

The interviewer marks down "yes" when the informants report experiencing at least one of these symptoms. The interviewer will underline the symptom or symptoms the informants claim to suffer.

7. Is your digestion poor? yes/no

Mark down "yes" when the informants answer that they feel sick every time they eat during the past 30 days. If they answer that they felt sick occasionally or on eating certain food, the interviewer should rate "no".

8. Do you have trouble thinking clearly? yes/no

Mark down "yes" when the informants say that during the last 30 days they have felt incapable of thinking clearly to the extent that they have not done their daily activities.

9. Do you feel unhappy? yes/no

Mark down "yes" when the informants say that they have felt constantly sad during the last 30 days.

10. Do you cry more than usual? yes/no

Mark down "yes" when the informants say that during the last 30 days they cry without any good reason and this constitute an unusual behaviour.

11. Do you find it difficult to enjoy your daily activities? yes/no

cause them problems and sufferings. The interviewer could also ask them if they enjoy their daily activities, which they will answer with a "yes" or "no". One should be careful to rate this question adequately.

12. Do you find it difficult to make decisions? yes/no

The interviewer can help the informants give a precise answer by asking the following questions: "Do you take your time deciding on what to do; do you make up your mind quickly?" These additional questions might make it easier for the informants to give an answer.

13. Is your daily work suffering? yes/no

Don't you like what you do? This question applies to those who work either outside or are occupied at home. It is not the intention of this question for example, to find out if the informants have trouble finding a job.

14. Are you unable to play a useful part in your life? yes/no

The interviewer could also ask "have you felt that no matter what you do, nothing useful or worthwhile will come out of it?"

15. Have you lost interest in things? yes/no

Have you felt that nothing is worthwhile any longer? Do things look less appealing than they had before and have you felt this during the last 30 days?

16. Do you feel that you are a worthless person? yes/no

Does everything you do turn out wrong, have you felt that everything you do is worthless.

17. Has the thought of ending your life been on your mind? yes/no

If the informants say "yes", the interviewer should ask if these thoughts or ideas are frequent. When have they thought of it, how would they do it, why should they? These questions can tell how serious the threat really is. These questions should be asked in a neutral tone of voice as some people might resent them.

18. Do you feel tired all the time? yes/no

Have you felt tired, weary, and weak without a good reason during the past 30 days?

19. Do you have uncomfortable feelings in your stomach? yes/no

If the informants answer "yes", ask them to tell you in their own words what they feel and if they have felt it in the lat 30 days.

20. Are you easily tired? yes/no

If the respondent's answers "yes", ask them to tell if they get tired doing the things that didn't seem to tire them before. If they answer that they have felt this way after running or climbing stairs, the interviewer will rate "no". Look at the answers they gave for question 18; be sure the answer is the same since those are identical items.