AIDS-RELATED BEREAVEMENT IN THE SOUTH AFRICAN CONTEXT: A STUDY OF KWAZULU-NATAL, DURBAN

Craig Demmer

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Submitted with the permission of the supervisor, Professor Vishanthie Sewpaul:

Abstract

Not only does South Africa have the largest number of people with HIV/AIDS in the world, it continues to have a high mortality rate associated with AIDS due to the limited availability of antiretroviral treatment in this country. While a body of empirical research has developed in the West on the issue of AIDS-related bereavement, it has limited applicability to the South African context where the daily lives of people infected with and affected by HIV/AIDS are markedly different to those in more developed countries in the West, in terms of the extent of HIV-related morbidity and mortality, poverty, stigma, availability of social support, gender inequality, medical treatment, welfare services and government policies.

An exploratory, descriptive study was therefore undertaken to examine AIDS-related bereavement experiences among adults in KwaZulu-Natal, Durban. Qualitative face-face interviews were conducted with 18 adults who had lost one or more significant others to AIDS. Qualitative face-face interviews were also conducted with eight professionals working in non-governmental organizations in KwaZulu-Natal that served people affected by HIV/AIDS to obtain their perspectives on the issue of AIDS-related bereavement among clients and how they were addressing this issue within their organizations. A social ecological framework was used to understand participants' experiences with AIDS-related bereavement.

Two major themes emerged: participants had to keep their grief to themselves and more urgent life stresses took priority in their lives. A conspiracy of silence existed as a result of the high level of stigma associated with HIV/AIDS and a perceived lack of both informal and formal support for those infected with and affected by HIV/AIDS. Grief was treated as a "luxury" in a sense and energies had to be focused on daily survival needs. Participants tended to suppress their emotions and relied on inner resources, in particular finding meaning in their loss and relying on their religious faith. Interviews with professionals confirmed these themes.

Recommendations are made at both the local and national levels to address AIDS-related bereavement. It is suggested that while individual and group interventions should be developed for those at risk for complicated grief as a result of an AIDS-related loss, the focus needs to be on structural changes such as reducing HIV-related stigma, combating poverty, encouraging men to play a more active role in the care and support of those who are ill with HIV/AIDS or bereaved by the disease, and improving the status and capability of the social work profession to respond to the HIV/AIDS epidemic within the South African welfare policy framework. Further research needs to be conducted on AIDS-related bereavement in the South African context, considering the magnitude of AIDS-related loss and bereavement and the scarcity of indigenous information about this issue. Collaborations between researchers, practitioners and the bereaved are encouraged both in South Africa and internationally to highlight the unique nature of AIDS-related bereavement in the South African context and to test the efficacy of indigenous strategies and interventions to address AIDS-related bereavement.

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PART ONE: INTRODUCTION

CHAPTER 1

Introduction

Without question, Acquired Immune Deficiency Syndrome (AIDS) is one of the most urgent health problems in the world today. The large number of people who have died of AIDS around the world is staggering. It is estimated that the disease has already taken more than 25 million lives worldwide (UNAIDS, 2004). Needless to say, this has resulted in a parallel epidemic of grief for those who have lost loved ones to AIDS.

South Africa is the most industrialized country in Africa and is regarded by many as "a first-world country in a third-world continent" (Travis, McFarlin, van Rooyen & Gray, 1999, p. 178). In South Africa, AIDS has reached crisis proportions. Not only does it have the largest number of people with HIV (Human Immunodeficiency Virus) or AIDS in the world (over 5 million), it has an extremely high AIDS mortality rate because the majority of people who are HIV-infected are denied access to life-prolonging treatment (Benatar, 2004). Most of those affected by HIV/AIDS in South Africa struggle with multiple stressors on a daily basis including extreme poverty, social stigma, violence, poor health care and inadequate social support. As we shall see, two decades of AIDS-related deaths in South Africa have resulted in a population of "hidden grievers"; people who hide their grief because of the fear, stigma and secrecy attached to the disease. It is in this context that social workers and others in the helping professions in South Africa are called upon to respond to the epidemic.

Research problem

Over the last two decades in the United States (US), a number of studies have been conducted to explore the bereavement experiences of individuals who have lost loved ones to AIDS. This research has mainly focused on gay men since they have been most affected by the HIV/AIDS epidemic in the US and other developed countries. But the make-up of the HIV/AIDS epidemic in vastly different in South Africa, and we know very little about the AIDS-related bereavement experiences and concerns of individuals in the local context (i.e., South Africa), and how to assist these individuals. There are valuable lessons we can learn from research on AIDS-related bereavement in developed countries, but at the same time we need to understand the unique stresses and needs of individuals in South Africa who have lost loved ones to AIDS. Interventions need to be developed that are tailored to the South African context to address the needs of those who have lost loved ones to AIDS in the past, as well as those who will lose loved ones in the future.

The roll out by the South African government of antiretroviral (ARV) treatment will hopefully drastically reduce AIDS-related mortality among South Africans. But the roll out has been extremely slow so far and most HIV-infected people still do not have access to these treatments ("South Africa needs to face the truth about HIV mortality", 2005). Also, it is important to note that ARV treatment will not work for everyone. People continue to die of AIDS-related causes in countries with widespread access to ARV treatment, though in far smaller numbers (Lewden et al., 2001; Welch, Morse & Adult Spectrum of Disease Project in New Orleans, 2002; Sabin, 2002). In the forthcoming era of ARV treatment in South Africa, social workers may have to help individuals come to terms with the fact that their loved ones succumbed to AIDS before they could benefit from these treatments, as well as assist those in the future who will grieve the loss of loved ones who did not respond to these treatments.

Research Questions

The aim of this study was to gain insight into and make discoveries about the means by which a sample of adults in KwaZulu-Natal, Durban grieved the loss of loved ones to AIDS. As far as I am aware, no such previous research has been done in the South African context and a qualitative, exploratory research design was therefore considered appropriate. This type of research often raises questions to be examined in subsequent studies (Marlow, 1998). In-depth interviews were conducted with 18 adults bereaved by AIDS as well as 8 providers in various non-governmental organizations (NGOs) in KwaZulu-Natal serving people affected by HIV/AIDS to get their perspectives on the phenomenon of AIDS-related bereavement.

Some basic facts about the geographical area from which participants were drawn: KwaZulu-Natal is one of nine provinces in South Africa and it has the largest population:

almost 9.5 million people. According to the 2001 census, the total population of South Africa is 44.8 million people (Statistics South Africa, 2003). Nearly 85% of the population in KwaZulu-Natal is Black African. Black Africans constitute more than three quarters of the population in South Africa. The home language of just over 80% of the population of KwaZulu-Natal is Zulu (Statistics South Africa, 2003). Durban is the largest city in KwaZulu-Natal with a population of over 3 million. The median annual income of working adults aged 15-65 in the city is R 20,695 ($3,111) (Wikipedia, 2005).

The specific research questions were as follows:

(1) What lessons can be learned from the literature on AIDS-related bereavement in the US?

(2) How is AIDS-bereavement different in South Africa due to the unique nature of the local context compared to that of the US?

(3) How have the needs of the AIDS bereaved been addressed up to now in South Africa from the perspective of individuals, local communities, non-profit organizations, professional groups (e.g., social work profession), and state/government policy?

(4) What is the extent of AIDS-related loss among participants in this study?

(5) What factors do participants perceive as influencing their bereavement in a negative or positive manner, looking at individual factors as well as the physical and social environment?

(6) What coping methods have participants used to deal with their grief?

(7) What personal meaning is attached to losing a loved one to AIDS?

(9) What are the main everyday concerns of participants?

(10) What are participants' attitudes about the response of their loved ones, their community, and the government to those affected by HIV/AIDS?

Conceptual Framework

Bronfenbrenner's (1979) social ecology model provided the theoretical framework for this study. The social ecology model focuses on the person, the environment, and the interaction between the two. According to this model, four major factors will influence the well-being of an individual bereaved by AIDS:

- *Person factors* that include the biological, personality, and intellectual characteristics of the individual.
- *Process factors* that include the types of interaction that occur among individuals.
- *Contextual factors* that include families, communities, cultures etc.
- *Time variables* meaning the changes that occur over time with regard to person, process and context variables.

The way in which a bereaved individual is influenced by these factors is dependent on the way these factors interact with each other. It was anticipated that contextual factors in South Africa would be extremely important in determining the bereavement experience of individuals who had lost loved ones to AIDS.

Bronfenbrenner (1979) postulated that "the ecological environment is conceived as a set of nested structures, each inside the next, like a set of Russian dolls" (p. 3). If an AIDS-related loss is viewed as the central focus of influence on the bereaved individual's life, the mesosystem, exosystem, macrosystem, and chronocsystem can be viewed as concentric circles surrounding the loss. A microsystem involves the behaviours and interactions of the bereaved individual in his/her immediate environment (e.g., home). A mesosystem involves interrelationships between the bereaved individual and other settings such the extended family, neighbours, friends, the community, the church. The exosystem includes those settings that influence bereavement but do not play an active role. Examples are the health and social welfare system. The macrosystem involves traditional and cultural beliefs about death, mourning and how to grieve. It also includes political and economic policies of the government regarding HIV/AIDS and the care and support of people affected by HIV/AIDS. Finally, the chronosystem includes political, cultural and social changes as well as medical advances over time that may influence the bereavement experience.

Stokols (1992) described several core assumptions underlying the social ecological perspective which I believe can be applied to the study of AIDS-related bereavement in South Africa as well as the development of strategies to address bereavement in the local context. First, the well-being of individuals is influenced by various factors in the physical environment (e.g., geography, technology) and social environment (e.g., culture, economics, politics). In addition, the well-being of individuals is influenced by a variety of personal attributes (e.g. behavioral patterns, psychological predispositions). Thus, a study of AIDS-related bereavement should explore the dynamic interplay among diverse environmental (e.g. poverty, stigma, lack of services, government response) and personal factors (coping capacity, history of loss, relationship to the deceased) rather than focusing only on environmental or personal factors.

Second, a study of AIDS-related bereavement should address the multidimensional and complex nature of human environments. Environments can be described in terms of their physical and social components as well as their actual or perceived qualities, and their scale of immediacy to individuals. Thus, this study examined factors in the individual's home, village, and community that influenced their bereavement (e.g., lack of privacy, friendship network, relationship with spouse/family members as well as others in the community, perceptions of the availability of support in the community).

Third, the social ecological perspective incorporates multiple levels of analysis (e.g., individuals, small groups, organizations) and diverse methodologies (e.g., medical exams, questionnaires, behavioral observations, epidemiological analyses) for assessing the well-being of individuals and groups who are grieving AIDS-related deaths. Thus, this study examined through qualitative interviews the nature of AIDS-related bereavement among individuals. Moreover, this study explored the influence of factors in groups/communities (attitudes toward AIDS among community members) as well as formal structures such as non-profit and governmental organizations (access to support services, outreach, welfare policies) on bereavement.

Fourth, the social ecological perspective incorporates a variety of concepts from systems theory (e.g., interdependence, homeostasis, negative feedback) to understand the dynamic interrelations between people and their environments. Thus, people-environment transactions are characterized by cycles of mutual influence, whereby the physical and social features of settings directly influence individuals' well-being/bereavement, and individuals in these settings modify the healthfulness/supportiveness of their surroundings through their individual and collective actions. Based on the findings of this study, strategies are proposed to address AIDS-related bereavement at various levels (e.g., individual, community, government) and through various means.

This is the first known study of AIDS-related bereavement using a social ecological approach. It seems the most appropriate framework to use for studying AIDS-related bereavement in South Africa considering the unique local context. In-depth interviews were guided by questions that explored the interdependence between grieving individuals and their environment (physical, economic, social). In order to understand the dynamics of bereavement among individuals bereaved by AIDS in a complex environment like South Africa, a multi-level analysis of factors influencing bereavement was considered warranted. Similarly, the development of strategies to help these individuals should incorporate awareness of these various levels of influence, and target interventions at these different levels using various methods.

Definition of Terms

For the purposes of this study, the following definitions were used:

AIDS (Acquired Immune Deficiency Syndrome): AIDS is an umbrella term for any or all of 26 known diseases and symptoms. When an individual has any of these diseases or has a CD4 or T4 lymphocyte count of less than 200 and also tests positive for antibodies to HIV, an AIDS diagnosis is given (Stine, 2004).

Antiviral: Means against virus; drugs that destroy or weaken a virus (Stine, 2004).

ARV (Antiretroviral therapy/treatment): Treatment with drugs designed to prevent HIV from replicating in an HIV-infected individual. Highly active antiretroviral therapy (HAART) is a drug regimen that includes multiple types of antiretroviral drugs (Stine, 2004).

Bereavement: The objective situation of having lost someone significant (Stroebe, Stroebe & Hansson, 1993).

CD4 (T4 cell): White blood cell with type 4 protein embedded in the cell surface –target cell for HIV infection (Stine, 2004).

Epidemic: Affecting many persons at once, outbreak or rapid, sudden growth or development (Stine, 2004).

Grief: The emotional response to one's loss (Stroebe, Stroebe & Hansson, 1993).

HIV (Human Immunodeficiency Virus): A retrovirus that is said to cause AIDS. The target organ of HIV is the CD4 subset of T lymphocytes which regulate the immune system (Stine, 2004).

HIV-positive: Presence of the human immunodeficiency virus in the body (Stine, 2004).

Mourning: Denotes the actions and manner of expressing grief, which often reflect the mourning practices of one's culture (Stroebe, Stroebe & Hansson, 1993).

Outline of Chapters

There are five sections: an introduction, literature review, methodology, analysis and discussion, and conclusions and recommendations. A brief description of each chapter follows.

PART ONE constitutes the introduction section and it consists of one chapter. Chapter One is an introduction to the study. The research problem is identified and specific research questions are listed. The conceptual framework of the study is briefly described and this is followed by a list of terms that appear throughout this study.

PART TWO is the literature review and it consists of three chapters. Chapter Two presents an overview of the HIV/AIDS epidemic in South Africa and attention is paid to factors that have influenced the spread of the disease in this country on the micro and macro levels. Statistics on AIDS-related mortality are also presented. Chapter Three provides an overview of the bereavement field. This includes concepts, theories and research. Developments in the bereavement literature are noted and there is a review of factors that influence grief as well as concepts such as disenfranchised grief and complicated grief which are relevant to those who have lost loved ones to AIDS. Chapter Four reviews the literature that pertains to bereavement associated with AIDS. It examines factors that often cause this type of bereavement to be more challenging than bereavement associated with other types of deaths.

PART THREE is the methodology section and consists of two chapters. Chapter Five describes the research methodology and includes a discussion of the sample as well as information relating to data collection, recording and analysis. This is followed by a discussion of how ethical issues were addressed. Chapter Six consists of a description of participants in the primary sample in the form of short profiles and this is followed by a summary of the demographic characteristics of participants and the nature of their losses.

PART FOUR is the analysis and discussion section and it consists of eight chapters. Chapters Seven through Thirteen focus on the primary sample (18 individuals bereaved by AIDS) while Chapter Fourteen focuses on a group of eight providers in NGOs serving people affected by HIV/AIDS in KwaZulu-Natal. Chapter Seven examines the socio-economic impact of AIDS-related deaths on households and how poverty often overrides emotional needs. Chapter Eight focuses on the plight of children who have lost family members to AIDS. Participants speak about their concerns for the fate of children, both the deceased's as well as their own. Chapter Nine describes the experiences of participants leading up to the death of a loved one and this includes an examination of their awareness that the person had AIDS and/or was dying, their role in caring for the person, attitudes about how the person was treated, and finally their experiences of burying the person. Chapter Ten examines the issue of secrecy and denial surrounding AIDS and a loss from AIDS. Factors contributing to this state of affairs are described. Chapter Eleven explores participants' perceptions of support (both informal and formal) available to those affected by HIV/AIDS. Chapter Twelve discusses the physical and psychological impact of losing a loved one to AIDS and the issue of multiple losses is covered. Chapter Thirteen examines how participants actually coped with their loss. Chapter Fourteen explores providers' experiences dealing with AIDS-related loss – among their clients as well as themselves. It includes a profile of the NGOs that were visited during this study and how they were addressing the needs of the bereaved. This is followed by a brief discussion of working conditions as reported by providers.

PART FIVE is the conclusions and discussion section and it consists of one chapter. Chapter Fifteen summarizes the main themes that emerged in this study. It discusses the need for interventions that are appropriate for the local context. The role of the social worker is explored against the backdrop of developments in the South African welfare system. Suggestions are made for the NGOs that were visited in this study in terms of how to enhance services to those bereaved by AIDS. The final section includes broad suggestions for South African social workers and other helping professionals in addressing AIDS-related bereavement.

PART TWO: LITERATURE REVIEW

CHAPTER 2

The HIV/AIDS Epidemic in South Africa

This chapter presents an overview of the HIV/AIDS epidemic in South Africa. This includes a description of the prevalence of HIV infection as well as AIDS-related mortality. Attention is paid to micro and macro factors that have influenced the spread of HIV/AIDS in South Africa.

AIDS Epicentre

South Africa has the unfortunate distinction of having the highest number of HIV-infected individuals in the world (UNAIDS, 2004). While Sub-Saharan Africa makes up 70% of the world's HIV cases, South Africa accounts for over 50% of new reported HIV cases in this region (Winter, Jacobs, Delate, & O'Malley, 1998). It is not surprising then that South Africa has been called "one of the AIDS capitals of the continent" (Campbell, 2003). In fact, it may be more accurate to describe it as *the* AIDS capital of the world. The first AIDS cases were reported in South Africa in 1982 (Department of National Health and Population Development, 1994). By 1990, there were 353 reported AIDS cases (Mitton, 2000). Fast forward to 2003 and there were 4.69 million South Africans living with HIV or AIDS (Rehle & Shisana, 2003). This is considered a low estimate actually and the real figure may be closer to 5.3 million (Dorrington and Johnson, 2002; UNAIDS, 2004). And there is no sign that the epidemic in South Africa is declining (UNAIDS, 2004).

Demographics

There has been much discussion about the nature and reliability of surveillance systems in South Africa that monitor the spread of HIV/AIDS in the population. The main source of our information about the epidemic in this country comes from the antenatal clinic HIV seroprevalence survey conducted by the Department of Health since 1990 (Department of National Health and Population Development, 1995). Rehle and Shisana (2003) cautioned that we must be careful when extrapolating from antenatal clinic data because there may be significant differences between the characteristics (and risk behaviors) of the pregnant women and the general population. There are also concerns about the sampling methods used. Dorrington and Johnson (2002) criticized the government's "reluctance to allow independent researchers access to this data or to explain in detail the methods used to derive the national and provincial figures" (p. 23).

In response to the need for more accurate data, the first national population-based or household survey of the prevalence of HIV in South Africa was conducted in 2002 (Nelson Mandela/Human Sciences Research Council Study of HIV/AIDS, 2002). The survey estimated that 11.2% of South Africans aged two years or older were living with HIV/AIDS in 2002. Contrary to antenatal clinic data from 2001, it was found that Free State, Guateng, and Mpumalanga had the highest prevalence rates (over 14%). KwaZulu-Natal which traditionally has been viewed as having the highest provincial HIV prevalence rate (based on antenatal clinic data) only ranked fourth, with approximately 11.7% infected. The other provinces had HIV prevalence rates ranging from 6.6% to 10.7%. Some other important findings were:

- HIV prevalence was higher among those living in urban informal settlements versus urban formal settlements and rural areas.
- HIV prevalence was highest for Africans. In the 15-49 year age group, 18.4% Africans were infected followed by 6.6% of Coloureds, 6.2% of Whites, and 1.8% of Indians.
- Those most likely to be infected were in the 25-29 year age group.
- In the 15-49 age group, females (17.7%) were more likely to be infected than males (12.8%).

According to a UNAIDS (2004) report, there are advantages and disadvantages to both antenatal clinic data and population-based survey data, but it is wise to remember that:

> ...there is no gold standard for HIV surveillance. All HIV estimates need to be assessed critically – whether they are based on a national survey or on sentinel surveillance data. Using all available data to arrive at HIV estimates ensures the best possible quality. (p. 22)

Studies of hospital admissions provide additional data on the epidemic. For example, a study within a tertiary hospital in Durban showed that HIV/AIDS was the single most common cause for admission to the adult medical wards (54% of patients were infected with HIV) and almost half the beds in these wards were being occupied by HIV/AIDS patients (Colvin, Dawood, Kleinschmidt, Mullick & Lallo, 2001). This means that there were far fewer beds available in this hospital for non-HIV patients, despite the fact that the number of beds in this particular hospital as well as the number of state hospital beds had not increased in recent years (Colvin et al., 2001). Another study of an urban hospital was conducted by Zwi, Pettifor, and Soderlund (1999) who examined pediatric admissions to Chris Hani Baragwanath Hospital in Guateng for the period 1992-1997. The main finding was that the proportion of children infected with HIV rose from 2.9% of admissions to 20% over this period. Also, HIV-infected children were more likely to stay longer in the hospital than uninfected children and were twice as likely to be readmitted. In another study, Floyd, Reid, Wilkinson, and Gilks (1999) found that AIDS cases had increased 43-fold at a rural hospital in Hlabisa District in KwaZulu-Natal between 1991 and 1998. These data demonstrate the huge burden that the epidemic has placed on the South African health care system.

Workplace surveys offer another source of information on HIV prevalence. For example, a large scale workplace survey was undertaken among 44,000 formally employed workers in South Africa, Botswana, and Zambia (Evian, Fox, MacLeod & Rosen, 2004). Prevalence of HIV among workers in South Africa was 14.5%. Among the three countries overall, HIV prevalence was highest among male workers, workers in mining and metal processing, and contract, unskilled and semi-skilled workers than skilled workers.

AIDS Mortality

The AIDS epidemic has been described as a "tidal wave of death approaching South Africa" (Ashforth, 2002, p. 124). It has become common in recent years to see headlines in newspapers around the world drawing attention to the high death toll associated with AIDS in South Africa such as: *Life Expectancy Plummets in Southern Africa*, *A Sadly Mounting Ritual* and *In South Africa, Only the Funeral Industry is Booming.* News reports have drawn attention to the fact that so many people are dying of AIDS there is no place to bury them. In Durban, a total of 51 of the 53 municipal cemeteries are officially filled to capacity and the city has started to "recycle" graves, placing corpses on top of old ones (Wines, 2004).

Official mortality data in South Africa are limited and there are serious concerns about the quality of data that are available (Kahn, Tollman, Garenne & Gear, 1999). For instance, there is often marked under-reporting of deaths as well as misclassification of the causes of death (Kahn et al., 1999). In response to the lack of reliable official statistics on AIDS mortality in South Africa, a report was released by the South African Medical Research Council in July 2001 titled *The Impact of HIV/AIDS on Adult Mortality in South Africa* (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001). The most important finding was that AIDS had become the leading cause of death in South Africa, and it was estimated that 40% of all adult deaths aged 15-49 were now due to HIV/AIDS. Another major finding was that women were more likely to die earlier than men. Female deaths peaked at 25-29 years and male deaths peaked at 30-35 years (Dorrington et al., 2001). A recent study of death registration data showed that the total number of adult deaths in South Africa rose by 40% in the past six years, and for women aged 20-49, there has been an increase of more than 150% (Bradshaw, 2004).

To get a sense of the gravity of the AIDS crisis in South Africa, we can compare the AIDS mortality rate in South Africa with that of the United States. In 2001 there were approximately 360,000 deaths from AIDS in South Africa (up from 200,000 in 1999) (UNAIDS, 2002; UNAIDS, 2000). In the same year, the *cumulative* number of AIDS deaths in the United States since 1981 was 467,910 (Centers for Disease Control and Prevention, 2003). By 2005, the cumulative number of AIDS deaths in South Africa is expected to reach 2.56 million (Rehle & Shisana, 2003).

South Africa is reported to have entered the "death phase" of the pandemic, meaning that the number of people dying of AIDS has begun to outstrip the number of new infections, ("South Africa in 'death phase", 2003). For instance, in KwaZulu-Natal, there will be approximately 160,000 AIDS deaths in 2005 and 140,000 new infections. By 2010, the gap is expected to widen and there will be roughly 200,000 AIDS deaths with 130 000 new infections (Dorrington & Johnson, 2002). If we continue on our current course with limited public access to antiretroviral (ARV) treatment, the annual number of deaths due to AIDS is projected to peak at 487,320 in the year 2008 (Rehle & Shisana, 2003). Between 2000 and 2010, it is estimated that anywhere from 5 to 7 million South Africans will die from AIDS (Dorrington et al., 2001). Furthermore, Rehle & Shisana (2003) projected that:

- Life expectancy at birth will hit a low of 45.6 years (this is 22 years less than it would be without AIDS) between 2005 and 2110.
- There will be over 2.5 million children orphaned by AIDS ten years from now.

Community-based studies provide important supplementary data on AIDS-related mortality in South Africa. For instance, Zwi et al. (1999) in their study of pediatric admissions to Chris Hani Baragwanath Hospital in Guateng found that 50% of ward deaths were due to HIV/AIDS compared to 7% in 1992. Looking at a different population group, Kruger and Bhagwanjee (2003) assessed changes in maternal mortality at the Johannesburg Hospital over two time periods: 1995/1996 and 2000/2001. They found that maternal mortality nearly doubled over five years at the hospital and this was linked to a marked increase in HIV/AIDS cases. By 2000/2001, HIV/AIDS had replaced hypertension as the most common cause of death among pregnant women at the Johannesburg Hospital.

In an effort to quantify the impact of AIDS on adult mortality in rural South Africa, Hosegood, Vanneste, and Timaeus (2004) conducted verbal autopsy interviews with the caregivers of individuals who had died in 2002. The study area was the rural district of Umkhanyakude in northern KwaZulu-Natal. Out of a total of 1,021 adult deaths (over 15 years of age) in 2002, it was determined that AIDS was the single largest cause of adult death (48%). Women appeared to be particularly vulnerable; AIDS was responsible for 52% of all female deaths and 44% of all male deaths. Furthermore, women under 30 years of age had higher AIDS-specific mortality than men. This study provides alarming evidence of the rise in AIDS-related mortality in rural areas of South Africa, especially when compared to earlier studies of mortality in rural areas such as the one by Kahn et al. (1999) of the Agincourt subdistrict in South Africa's north-east. Also using verbal autopsies, they investigated 932 deaths for the period 1992-1995 and found that AIDS was responsible for 6% of all adult deaths.

Notkola, Timaeus, and Siiskonen (2004) identified an interesting and low-cost source of data that can be used for studying the impact of AIDS on mortality. They analyzed death records from the registers of eight Evangelical Lutheran parishes in northern Namibia and compared them with marriage and birth records of parishioners. Based on records of couples who married between 1956 and 2000 as well as children born, the researchers noted a pattern of mortality that was consistent with the impact of AIDS on the rest of the population. Child mortality increased more than six-fold between 1991 and 2000. Adult mortality for women was 3.5 times higher in 2000 than in 1993, and for men it was 2.5 times higher.

Contributing Factors

A frequently asked question is: 'Why is South Africa, a comparatively wealthy and developed country in Africa, so badly affected by HIV/AIDS?' Heinecken (2003) stated that the reasons for the spread of the epidemic in Southern Africa overall are complex but offered this explanation for South Africa:

> The main factors spreading the epidemic are the breakdown of the social fabric of society as a consequence of apartheid, the migrant labor system, the good transport infrastructure leading to high population mobility, the large disparities in income, and the low level of education. Other factors include high levels of prostitution and sexually transmitted disease, resistance to condom use, and social norms permitting high numbers of sexual partners. (p. 283)

There has been growing recognition among researchers over the past decade of the importance of acknowledging and understanding the "contextual backdrop" of HIV/AIDS in South Africa (Bernstein & van Rooyen, 1994; James, 2002). Campbell (2003) indicated that "the forces shaping sexual behavior and sexual health are far more complex than individual rational decisions based on simple factual knowledge about health risks, and the availability of medical services" (p. 7). She stressed the importance of understanding both micro-level factors (e.g. attitudes, cognitive processes, perceived vulnerability) and macro-level factors (e.g. poverty, gender inequalities) and she asserted that "each of these perspectives forms an essential frame in the kaleidoscope of factors that are implicated in the development and persistence of the HIV epidemic..." (p. 7).

However, we are only just beginning to understand how historical, social, political, and cultural factors interact to shape the epidemic in South Africa (Delius & Walker, 2002). According to Campbell (2003), inadequate attention has been paid to how micro and macro factors interact at the community level. I will briefly review some of the main factors that appear to have contributed to the extent and severity of the HIV/AIDS epidemic in South Africa from the micro to the macro level.

Sexual Knowledge, Attitudes and Behavior of Adults

A significant body of research has developed focusing on HIV/AIDS awareness and sexual risk behaviors among adults and youth in South Africa. But the problem is that many studies report contradictory findings, making it confusing where we stand in terms of HIV prevention needs. For example, Dorrington and Johnson (2002) asserted that a significant proportion of South Africans lacked basic knowledge about HIV/AIDS. In contrast, the 2002 national HIV/AIDS Household survey found that overall South Africans had "good knowledge of key aspects of HIV/AIDS information" (Nelson Mandela/Human Sciences Research Council Study of HIV/AIDS, 2002, p.15).

A significant weakness of recent studies of risk behaviors among South Africans (Nelson Mandela/ Human Sciences Research Council Study of HIV/AIDS, 2002; Simbayi, Chauveau, & Shisana, 2004) is that few have included any items relating to specific sexual behaviors (e.g. receptive oral sex, insertive anal sex, mutual masturbation, kissing etc). This is troublesome since there are varying degrees of associated risk along the continuum of sexual behaviors. According to Brody and Potterat (2003), health warnings in Sub-Saharan Africa tend to avoid mentioning anal sex, and it is believed that a significant proportion of both women and men engage in receptive anal intercourse. The glaring omission of questions relating to specific types of sexual behavior is also evident in recent surveys of risk attitudes and behaviour of youth (Peltzer, 2003; Taylor, Dlamini, Kagoro, Jinabhai & de Vries, 2003). This needs to be addressed in future surveys.

In addition, a subject that has been virtually ignored by researchers and those involved in HIV prevention efforts in South Africa concerns male-male sex. In his case study of same-sex sexuality in Dakar, Senegal, Teunis (2001) asserted that "male same-sex sexuality is more prevalent on the African continent than the literature on African sexuality suggests" (p. 180). More specific to the local context, Niehaus (2002) conducted interviews with former mineworkers and prisoners in Impalahoek, a village in the Bushbuckridge area of the South African lowveld, and indicated that "contrary to popular assumptions, male-male sex is extremely pervasive in both institutions and frequently takes the form of anal intercourse" (p. 94).

In Southern Africa, several politicians have made homophobic remarks, notably Robert Mugabe, the President of Zimbabwe and his Namibian counterpart, Sam Nujoma, as well as Kenneth Meshoe, the leader of the African Christian Democratic Party (Teunis, 2001; Niehaus, 2002). This hardly helps prevention efforts targeting men who engage in same sex behavior. There are such limited data available on risk behaviours among men who have sex with other men in Africa but evidence provided by both Teunis (2001) and Niehaus (2002) indicates that these men have inadequate knowledge about AIDS and a large proportion of them do not use condoms when engaging in anal intercourse. Both authors urged that we need to be more open about same sex sexuality and that we need to recognize that male-male sex is a high risk activity for the transmission of HIV.

Too few surveys have inquired about sexual behaviours with partners of the same sex; at best there may be a single question asking whether or not the respondent ever engaged in homosexual intercourse (Simbayi, Chauveau, & Shisana, 2004). The percentage of respondents who indicated in these surveys that they engaged in homosexual intercourse has been extremely (and suspiciously) low. For example, in the national HIV/AIDS Household Survey, 1.1% of youths 15-24 years of age indicated that they had at least one sexual experience with a member of the same gender in the past 12 months (Simbayi, Chauveau, & Shisana, 2004). Similarly, in the survey by Peltzer (2003) of a rural adult population, only two respondents out of a total of 398 adults (155 males and 243 females) reported having had a same sex partner (and they had not engaged in penetrative anal intercourse in the past 12 months). The social desirability bias inherent in these self-report surveys requires that we view these kinds of figures with caution.

Despite these flaws, recent research suggests that adult South Africans continue to put themselves at risk. For example, a study of female sex workers in the Limpopo Province, Peltzer, Seoka, and Raphala (2004) showed that although three quarters had been exposed to HIV interventions, most of them demonstrated inadequate knowledge of HIV prevention methods, some incorrect beliefs about HIV transmission, inconsistent condom use with paying partners, and poor condom use with regular partners. Olley, Seedat, Gxamza, Reuter and Stein (2005) examined the prevalence of unprotected sex in a sample of men and women in Cape Town who were recently diagnosed with HIV. Two thirds had been sexually active in the six months before the study and over half (54.5%) had not used a condom the last time they had sex. Individuals who had a shorter duration of HIV infection and who were more likely to engage in denial tended to have unprotected sex.

What seems to be evident from a range of studies with diverse population groups (e.g., school age youth, university students, adults, sex workers, teachers, mineworkers) (Taylor et al., 2003; Peltzer, 2003; Wojcicki & Malala, 2001; Varga, 2001; Maharaj, 2001; Macheke & Campbell, 1998; Smith, Visser & Akande, 1998; Mwamwenda & Jadezweni, 2000; MacPahil & Campbell, 2001; Peltzer & Promtussananon, 2003) is that while AIDS awareness seems to have increased over the past decade, condom use is still far too low given the pervasive and lethal nature of the epidemic in South Africa. In their review of HIV prevention programmes in South Africa, Harrison, Smit, and Myer (2000) concluded that "currently there is a substantial gap between high levels of knowledge and low levels of preventive practice" (p. 283).

Sexual Knowledge, Attitudes and Behavior of Children and Youths

Eaton, Flisher and Aaro (2003) reviewed a total of 75 research papers on sexual behavior among South African youth and they concluded from this review that although the majority of youth knew that AIDS was a fatal, sexually transmitted disease, there were serious gaps in their knowledge about the nature of HIV, the modes of transmission and ways to prevent infection (including proper use of condoms). A survey by Strydom

(2003) of high school students throughout the North West Province confirmed this trend. When asked how they regarded their knowledge of AIDS, 70% of respondents said "uncertain" and "inadequate." Macintyre, Rutenberg, Brown, and Karim (2004) surveyed 2,716 adolescents aged 14-22 in Durban Metro and Mtunzuni in KwaZulu-Natal to explore factors that influenced their perception of HIV risk. Twenty percent of respondents with high risk behaviors did not perceive that they were at risk for HIV infection. Factors predicting increased perception of risk among adolescents who reported current risky behavior were: less confidence to use a condom for males, older age for females, living in a household with a chronically sick member for females, and willingness to be a friend with a person with AIDS for males. Among male and females not engaged in current risky behavior, perception of risk was higher when it was perceived that adults in the community thought the youth were at risk. Based on their findings, Macintyre et al. suggested that future HIV prevention efforts focus on involving parents and other adults in helping adolescents identify risk behavior and to encourage them to protect themselves. Bernardi (2002) similarly stressed the important role the social network can play in influencing HIV risk perception in her study of adults in Western Kenya.

In their review, Eaton et al. also found that while most youth were not promiscuous, more than half of those who were sexually active reported not using condoms at all. Taylor, Dlamini, Kagoro, Jinabhai, and de Vries (2003) reported a similar finding in their survey of high school students in rural high schools in KwaZulu-Natal. Thirty percent of students were sexually active and only 53% had used a condom in the past month. This is consistent with the national HIV/AIDS Household Survey which reported that 57% of males and 46% of females aged 15-24 had used condoms at last sexual intercourse (Nelson Mandela/Human Sciences Research Council Study of HIV/AIDS, 2002). The authors of the latter report prefaced this finding with the comment that condom use among this group was "high" (p. 15). It seems odd that anyone would consider condom use to be high when only about one half of youth are using condoms while living in a country where their chances of becoming infected are extremely high.

A recent study by Anderson et al. (2004) painted a deeply worrisome picture of views about HIV risk among South African school pupils. The researchers conducted a huge, cross-sectional study of 269,705 pupils across 1,418 South African schools and findings included the following:

- 59.6% believed that condoms could help prevent HIV infection.
- 15.7% of males and 14.4% of females said they would not tell their family if they were HIV-positive.
- 15% said they would have unprotected sex and 15.7% said they would spread the virus intentionally.
- 12.7% believed that sex with a virgin could cure HIV or AIDS.

Simbayi, Chauveau, and Shisana (2004) presented a more optimistic picture of the HIV/AIDS crisis among youth, however. In a recent report using data collected as part of the national HIV/AIDS Household Survey, they asserted that South African youths are "making positive behavioral responses to the HIV/AIDS epidemic" (p. 613), especially when compared to the findings reported by Eaton et al. (2003). Simbayi, Chauveau, and Shisana argued that Eaton et al.'s review of studies on sexual risk behavior among South African youth did not provide an accurate picture of the current status of the behavioural responses of South African youth. They asserted that most of the studies that were reviewed by Eaton et al. were small in scale, focusing on particular groups known to engage in high-risk sex, and furthermore many of the studies predated the implementation of major prevention programmes in South Africa. Simbayi, Chauveau, and Shisana proceeded to offer recent data on sexual behavior among 2,430 youths aged 15-24. To summarize, their main findings for both males and females were:

- The average age of first sexual experience was 16.5 years.
- The majority (86.4%) had been sexually active over the past 12 months.
- Over two-thirds (66.6%) had used a condom during their lifetime.
- Just over half (52.8%) had used a condom at last intercourse.
- Over two-thirds (68.9%) reported ever discussing HIV prevention with their sexual partner.
- The majority (81.6%) had never done an HIV test.
- The majority (84.4%) did not know their HIV status.

Simbayi, Chauveau, and Shisana may have interpreted their findings in a more positive light than was truly warranted. For example, they made the sweeping and not totally accurate statement that "the majority of both male and female youths in the present study reported that they were using condoms and that they also had discussed HIV/AIDS with their partners…" (p. 617). No data were provided that would lead one to conclude that youths were consistently using condoms or that they discussed HIV prevention with every partner. There is a big difference between reporting to use condoms in one's lifetime (or even in the past 12 months) and using them every time one has sex. Again, the fact that only one half of respondents used a condom at last intercourse is hardly reassuring in a country with an extremely high HIV prevalence rate. Furthermore, not nearly enough attention was paid in their discussion to the implications that the majority of youths had not been tested and that they were not aware of their HIV status. The authors also neglected to discuss what I consider to be an important finding - that females from poorer household economic situations had more sexual experience. The implications of this in terms of HIV risk and prevention deserved further comment. Simbayi, Chauveau, and Shisana concluded by asserting that "it is nonetheless still critical to intensify prevention campaigns for current youth" (p. 617). While I wholeheartedly agree with this statement, it does appear somewhat inconsistent with the way they interpreted their data.

Another report using data collected from the 2002 national Household Survey was recently published by Brookes, Shisana, and Richter (2004) and it focused on HIV prevalence, HIV knowledge and risk factors for HIV infection among youth under 18 years of age. Data were analyzed for 3,988 children and here are some of the more important findings:

- 5.4% of children 2-18 years of age were HIV-infected.
- Among children 12 to 14 years of age, only half agreed that HIV could be transmitted through unprotected vaginal sex.
- Just over two-thirds of children said that condoms protect against contracting HIV.
- Two fifths of children reported that boys sexually harass girls.
- 15% of children reported that male teachers proposed relationships with students.

The authors of the report concluded that correct knowledge about HIV/AIDS was deficient and communication about sexual matters was inadequate, particularly for boys and by fathers. The most recent review of research on sexual behaviour among adolescents in South Africa by Hartell (2005) draws this bleak conclusion: "...despite the efforts of researchers, there has been no significant change in the rate of infection among adolescents in South Africa" (p. 180).

Sexually Transmitted Infections (STIs)

A significant correlation between STIs and HIV prevalence was confirmed in the 2002 national HIV/AIDS Household Survey (Nelson Mandela/Human Sciences Research Council Study of HIV/AIDS, 2002). Among those who had been diagnosed with an STI within the past three months, 38.9% were found to be HIV-positive compared to 13.2% who did not have an STI in the past three months. The high levels of STI infection in South Africa are indeed worrisome. In 1996, there were as many as 15,000 cases of syphilis per 100,000 in South Africa, compared to 15 cases per 100,000 in the United States and the United Kingdom (Pham-Kanter, Steinberg & Ballard, 1996). Other shocking data were: 12% of men had an STI within the past three months (Department of Health, 1999), and 25% of women living in rural areas of KwaZulu-Natal reported having had at least one STI (Wilkinson et al., 1999).

The Status of Women

Women are not only more biologically vulnerable to HIV infection but their status in society raises their risk further. Despite South Africa's progressive constitution, the balance of power remains weighted heavily toward men. According to Walker, Reid, and Cornell (2004):

> Young African women are the poorest, most economically marginalized and least educated sector of the South African population. This places them at the bottom of the health pile and renders them particularly vulnerable to HIV/AIDS. (p. 40)

The widespread oppression, violence and rape of women in South Africa are troublesome. There is a strong correlation between sexual and other types of abuse and women's chances of becoming HIV-infected (Garcia-Moreno & Watts, 2000). For many men, sex is a means to exert control over women. It is very difficult for women to insist on condom use because of the threat of violence (Walker & Gilbert, 2002; van Niekerk, 2001; Walker, Reid, & Cornell, 2004). The statistics on sexual abuse of women are alarming. South Africa is reported to have the highest per capita reported rape rate in the world with approximately one million rapes occurring each year (Rape Crisis Cape Town, 2001). It has been estimated that one third of all women in South Africa will be sexually assaulted or raped in their lifetime (Cook, 1994). The victimization of women begins at an early age; a number of studies have shown that females are coerced into sexual activity at an early age against their wishes (Vundule, Maforah, Jewkes & Jordaan, 2001; Ntlabati, Kelly, & Mankayi, 2001). According to a recent national survey, 28% of young women reported that their first sexual experience was unwanted and 10% said they had been forced to have sex (Reproductive Health Research Unit, Medical Research Council, 2004).

The brutalization of women is compounded by the added risk of being infected by the perpetrators. Among women attending antenatal clinics in Soweto, HIV infection was discovered to be more prevalent among women who had been physically abused by their partners than those who had not (Dunkle et al., 2004a). According to Kalichman and Simbayi (2004a), there is a close association between sexual assault and risk for HIV infection. In a street survey of women living in an African township in the Western Cape, they reported that 44% of respondents had a history of sexual assault. Respondents who had been sexually assaulted were more likely to have unprotected vaginal intercourse, lower levels of protected anal intercourse, more likely to fear asking their partners to use condoms, more sexual contacts involving blood, and more STIs and genital ulcers.

South Africa's risky sexual culture poses an immense challenge for HIV prevention efforts. For example, Leclerc-Madlala (2001) characterized Zulu sexual culture as consisting of the following:

> …gender inequity, transactional sex…multiple sexual partnerships, lack of discussion on matters of sexuality in the home and between sexual partners, the conditioning of both men and women to accept sexual violence as 'normal' masculine behavior along with the 'right' of men to control sexual encounters, and the existence of increasingly discordant and contested gender scripts. (p. 41)

A recent survey of HIV prevalence among young South Africans provided disturbing data on the vulnerability of young women. In the age group 20-24 years, 24.5% of women surveyed were HIV-infected, compared to 7.6% of men (Reproductive Health Research Unit, Medical Research Council, 2004). Overall, women made up 77% of South Africans under 30 years of age who were living with HIV (Reproductive Health Research Unit, Medical Research Council, 2004). Karim (1998) acknowledged that there are no immediate solutions to reducing women's vulnerability to HIV infection. Furthermore, he asserted that "any attempt to reduce women's vulnerability and risk has to focus on structural changes, development and the power imbalances in society" (p. 24).

Other researchers have also stressed the importance of changing the power imbalances between men and women in South African society to fight HIV/AIDS (Ackermann & de Klerk, 2002). The important question is how do we make these types of recommendations a reality? Structural changes do not occur overnight and recommendations of this sort seem rather abstract for those on the frontlines of HIV prevention. Albertyn (2003) analyzed gender inequality in South Africa through the lens of HIV/AIDS, and offered preliminary suggestions for translating theoretical insights about gender inequality into political strategies in the local context. Jewkes, Levin, and Penn-Kekana (2003) adopted a more cautious approach to the issue of gender inequality and HIV/AIDS and recommended that we first need to do more research "to explore more critically the relationship between gender inequalities and HIV prevention" (p. 132).

The Sexual Abuse of Children

The widespread abuse of children in South Africa places these children at risk for HIV infection. The issue of child rape has received a great deal of media attention in South Africa and abroad because of several high profile baby rapes in recent years (Meier, 2002). The gang rape of a nine-month old baby by six men in 2001 followed by the gang rape by four men of an eight-month old girl provoked a public outcry and stimulated debate about the culture of sexual violence that pervades South African society. Richter (2003, p. 393) asserted that the rape of babies and toddlers (under three years) has reached epidemic proportions and she quoted the following editorial in a Durban newspaper that sums up the crisis:

> 'South Africa is clearly in the grip of a near-psychotic wave of sexual and other violence against children (and against women) which runs counter to the values and traditions of every section of society. It points to a deep-seated social/psychological dysfunctionality which requires urgent expert analysis and the adoption of social and psychological measures to address it. There will be no easy answer.' (Mercury, 2003).

Meier (2002) painted a gloomy picture for the future of South Africa and asserted that "with an increasing number of children left without parents due to AIDS, cultural myths regarding rape, and economic downturns, the violence of child rape will continue to take its toll" (p. 534). Lalor (2004) provided an alarming estimate: approximately 6% of all children in high HIV-incidence countries in Sub-Saharan Africa will be sexually abused by an HIV-infected perpetrator before the age of 18.

A study by Anderson et al. (2004) provided data about sexual violence and HIV risk among a national sample of South African pupils. Overall, 8.6% of pupils said they had been forced to have sex in the past year and one third of them worried that they were HIV-positive. Pupils who had been sexually abused were more likely to state that they would not take an HIV test and would not inform their family if they were HIV-positive; and they also reported that they would intentionally spread HIV if they were HIV-positive. Youth who had been forced to have sex were also more likely to say they had forced someone else to have sex. Perpetrators were more likely to have misconceptions about sexual violence (e.g. girls enjoy being raped, girls mean yes when they say no) and HIV risk (e.g. sex with a virgin can cure HIV or AIDS, condoms do not protect against HIV).

Poverty

A great deal of attention has focused on poverty in relation to HIV/AIDS. But it is important to distinguish between viewing poverty per se as the cause of AIDS (as propagated by President Mbeki) and viewing it as the context within which the epidemic thrives. Van Niekerk (2001) asserted that:

> Poverty, with its accompanying side-effects such as prostitution (i.e., the need to sell sex for survival), poor living conditions, poor education, poor health and poor health care, are major contributing factors to the spread of HIV/AIDS. (p. 146)

Phatlane (2003) emphasized the importance of drawing "attention to the role that apartheid-created poverty plays, not in the causation, but in fueling and driving the epidemic" (p. 77). South Africa suffers from an extremely high unemployment rate. According to the Labour Force Survey the official unemployment rate was 41.2% as of March 2004 (Statistics South Africa, 2004). Unemployment levels are higher among Black Africans and women. Nattrass (2004), in a study of adults in Khayelitsha-Mitchell's Plain in Cape Town, indicated that 72% of the unemployed agreed with the statement: 'I feel useless and depressed because I do not have a job'.

With scarce resources, those in extreme poverty do not have access to proper treatment for STIs (Dorrington & Johnson, 2002). Poverty can lead to a desperate need to sell sexual services, especially among women. Those who are involved in 'survival sex' (i.e., trading sexual favours out of desperation) face increased vulnerability to HIV infection (Wojcicki, 2002; Nattrass, 2004). Dunkle et al. (2004b) investigated the prevalence of such transactional sex among women attending antenatal clinics in Soweto. They found that 21.1% of women in their study had engaged in sex with a non-primary male partner in exchange for material goods or money. Furthermore, women who reported past experience of violence by male intimate partners were more likely to report transactional sex. Transactional sex was associated with HIV seropositivity after controlling for lifetime number of male sex partners and length of time a woman had been sexually active. Crothers (2001) captured the essence of the problem:

> ...poverty increases the chances of weakened and scared bodies providing a higher risk of catching HIV/AIDS, it decreases the possibilities of using contraceptives...and poverty severely hampers the possibilities of prolonged resistance to the disease. (p. 17)

The prospect of confronting an epidemic embedded in a context characterized by devastating poverty, deprivation and illiteracy is daunting. Van Niekerk (2001) provided a poignant example of trying to reach a poor, isolated, illiterate woman and communicating the complexities of HIV/AIDS to her:

> How ...do you explain that she might become devastatingly ill simply from having sex with her husband, who is a migrant labourer, and that it is best to have them both tested? She might be ill already, only she'll not yet know it...There are drugs that can help her, only they are unaffordable for a person in her position...This woman will, in all probability, either not understand what is being communicated to her, not believe it, or shrug it off as just one of the many hazards that she has to face in order to continue her struggle for survival. (p. 153)

Nattrass (2004), who is an economist at the University of Cape Town, is adamant that a major component of any effective HIV prevention strategy should be finding ways to alleviate poverty. She cited a finding from a survey that was conducted in seven Southern African countries from 1999 to 2000. Respondents were asked: 'What are the most important problems facing this country that the government should address?' Despite the high HIV prevalence rates in these countries as well as associated mortality, economic issues (particularly job creation) were identified as the most important. This held true even for respondents who knew someone who had died of AIDS.

There is ample evidence of a relationship between high levels of illiteracy in certain communities and HIV infection. Phatlane (2003) noted that it was no coincidence that one of the hardest hit areas of the epidemic in South Africa – the Hlabisa District in KwaZulu-Natal – also had a very high level of illiteracy. National surveys have shown lower levels of sexual activity among better educated youth and lower rates of HIV infection among those with tertiary educational qualifications versus only school-level qualifications (Lovelife, 2000; Nelson Mandela/Human Sciences Research Council Study of HIV/AIDS, 2002). Also, those occupying more skilled jobs are less likely to be infected (Dorrington, 2001; Evian, 2003).

Migration and Social Disruption

During the Apartheid era, countless men, women, and children were forced from their homes and relocated to the most inhospitable areas of the country. Faced with enormous hardship in these areas that included extremely limited agricultural and employment prospects, many people particularly men had no choice but to seek work outside of these homelands as migrant workers. In 1990, it was estimated that more than 2.5 million migrants, drawn from rural areas and surrounding countries, were working in factories, farms and mines, (Zwi & Bachmayer, 1990). The Apartheid regime that had created this vast system of migrant labour knew about the disruptive effects of this system on families, individuals and communities but chose not to care. Neither did they care about the threat of AIDS. Opponents of Apartheid voiced their fears early on about the impact of the migrant labour system on the spread of AIDS. For example, Seftel (1988, p. 20) quoted newspaper editor Percy Qoboza who warned that:

> South Africa, through its mining industry, may soon become the world's flashpoint for AIDS. And unless the present [government] migratory labor system is reviewed with special attention paid to traffic from African countries plagued by the disease, an AIDS bomb is ticking in our mines.

The migrant labour system institutionalized the factors that facilitated the spread of

AIDS, namely long absences of men from their spouses and girlfriends and single sex hostels that led to an explosion of casual sex relationships, particularly between migrant workers and prostitutes (Seftel, 1988). Those who became infected then passed the virus on to their partners when they returned home.

Changing place of residence has also been shown to be a risk factor for HIV. Abdool Karim, Abdool-Karim, Singh, Short, and Ngxongo (1992) studied a rural community in KwaZulu-Natal and found that people who had recently changed place of residence were three times more likely to be HIV-positive than those who had not. The return of soldiers from military bases in areas of high HIV prevalence has also likely contributed to the rapid spread of the epidemic in South Africa (Dorrington & Johnson, 2002). Heinecken (2003) described the role of soldiers in the epidemic:

> Of all the sectors of society, they are one of the core transmission groups and are highly susceptible and vulnerable to the impact of HIV / AIDS. Susceptible because, like the factors that drive the epidemic in society, they are highly mobile, face frequent dislocation, are prone to casual sex, and are known for their high-risk behavior. Vulnerable because they deploy in socially disrupted and conflict zones that provide the environment for the spread of the disease. (p. 285)

Failure of HIV Prevention Efforts

Despite increasing awareness about HIV/AIDS among South Africans, there are enormous challenges facing those involved in HIV prevention work. An AIDS expert was recently quoted in a newspaper article as saying: "I don't think we yet have a handle on changing people's sexual behavior. So as a nation, we are in serious trouble" (Cohen, 2004, p. 3).

A number of attempts have been made over the past decade to prevent HIV infection among South Africans most at risk. Prevention efforts have been implemented in South Africa at various levels (national, provincial, non-governmental organizations) and in different settings (e.g. schools, clinics, urban areas, mines) (Harrison, Smit & Myer, 2000). But the sad reality is that few programmes have resulted in dramatic reductions in

HIV risk behavior among South Africans (Harrison, Smit & Myer, 2000; Campbell, 2003; Peltzer, Seoka, & Raphala, 2004). We only have to look at the statistics to see that the rate of HIV infection in this country has not abated (Nelson Mandela-/Human Sciences Research Council Study of HIV/AIDS 2002; Campbell, 2003).

HIV prevention education with youth in schools has not been without its share of problems. Common obstacles encountered are: scarce resources, conflicts between teachers' priorities and those of HIV education programmes, old-fashioned teaching methods that do not promote critical thinking skills around HIV, struggles over "ownership" of peer education programmes, teachers' preparedness and comfort level teaching about AIDS-related topics, motivations of peer educators, unequal gender dynamics among the peer educators that mirror the larger society, negative attitudes from other students toward peer educators, and lack of awareness among parents and religious groups about youth sexuality and the vulnerability of youth to HIV infection. (Peltzer & Promtussananon, 2003; Campbell, 2003; James, 2002; Campbell & MacPail, 2002; Sewpaul & Raniga, 2005).

The country's higher educational institutions have also been sluggish in responding to the HIV/AIDS epidemic and a significant change in attitudes only began in 1999. Through a comprehensive analysis of these institutions' policy documents and practical, programmatic responses (e.g., condom distribution, educational programmes, counseling, campus health care), Martin and Alexander (2002) concluded that at this time "no single university provides a model approach to HIV/AIDS that others should follow" (p. 343).

Researchers and practitioners are increasingly recognizing that the extreme complexity of the HIV/AIDS epidemic in South Africa requires that prevention efforts do not merely focus on individual behavior change but rather are widened to incorporate social issues that influence risk behavior. Campbell (2003) suggested that individualistic biomedical and behavioral perspectives alone have limited potential for informing interventions in highly marginalized communities. Thus, it is important to understand the social context when designing HIV prevention programmes (Aggleton, 1993). Prevention efforts cannot ignore the social and economic inequalities that exist in South African society such as poverty, unemployment, gender inequalities, and inadequate housing, education and health services.

Campbell (2003) recommended that long term measures be accompanied by more easily achievable short-term measures (e.g. detecting and treating STIs) and medium-term measures (e.g. peer education programs and condom distribution). In this vein, Campbell and her colleagues developed a community-led HIV prevention project in the goldmining region of Summertown that has been in existence since 1997. The focus of this community participatory project was to reduce HIV-transmission through three main activities: STI control, community-led peer education and condom distribution, and collaboration between stakeholders at different levels. The project was aimed at not only mineworkers but also other members of surrounding communities including sex workers and young people in schools. Campbell and her colleagues have written several publications about this well-funded, high-profile project (Campbell & Mzaidume, 2002; Campbell, Williams & Gilgen, 2002; Campbell & Williams, 1999), and these publications culminated in a book by Campbell (2003) titled *Letting Them Die – Why HIV/AIDS Prevention Programmes Fail.* The reason why I focus on the Summertown project is that even though it was well funded, "well-intentioned and technically well-informed", it had limited success (Campbell, 2003, p. 15). This is worrisome for those involved in HIV prevention work. The Summertown project went beyond individualistic perspectives and embodied community goals such as promoting community-led peer education and partnerships with multi-stakeholders, all with the intent to create a context that would promote healthy behaviors such as supporting the use of condoms and STI clinics. According to Campbell, "the most damning proof of lack of Project success over the three-year research period is the lack of evidence of any reduction in STI levels" (p. 185). Campbell provided a refreshingly honest and sobering assessment of the difficulties inherent in developing HIV prevention programmes in the South African context. She indicated that "what the Summertown experience shows is that community interventions are *extremely difficult to implement…*" (p. 187). Campbell cited several main obstacles that prevented the Summertown project from being successful, but two obstacles seemed to play a large role in undermining the project overall: (a) the way poverty, gender inequalities, stigma and denial are so deeply entrenched in the "social fabric of life" in ways that facilitate the transmission of HIV, and (b) the lack of political will - meaning the lack of motivation and commitment by individuals, groups as well as formal government to take personal ownership of the problem.

The Response of the Government

According to Heinecken (2003), three main things have characterized the epidemic in South Africa: "its uncontrolled spread, the lack of a coherent policy to deal with it, and the failure of public prevention programs" (p. 295). The government's role in the epidemic has received much attention and criticism both within the country and abroad (van Niekerk, 2001; Walker, Reid, & Cornell, 2004; Benatar, 2004). Before discussing this further, we should go back in time and consider how the apartheid government responded to HIV/AIDS when it first appeared. According to Nattrass (2004), "the history of AIDS policy in South Africa is a sorry tale of missed opportunities, inadequate analysis, bureaucratic failure and political mismanagement" (p. 41). Phillips (2003) asserted that the apartheid government was just as negligent by failing to respond appropriately to the growing HIV cases. In an early paper analyzing the role of the Apartheid government in addressing HIV/AIDS, Seftel (1988) criticized the government for its 'irresponsible and ineffectual way in which it has responded to the AIDS crisis' (p. 22). It was predicted that the government would use the virus to serve its political agenda:

> As long as the high-profile policy of black population control exists, there can be no reason for us to believe that the government will act differently to curb a disease that will ultimately achieve what war, forced removals, resettlement, the bantusan "homeland" policy, township massacres, severing township utilities, prohibitive rises in hospital tariffs, detention without trial, assassination squads, and sterilization programs have failed to do. (p. 22)

Grundlingh (2001) reviewed early attitudes and responses to HIV/AIDS in South Africa. The first AIDS cases were brought to the public's attention after the death of two homosexual flight attendants, one in August 1982 and the other in January 1983. From then until late 1987, the prevailing attitude of the government, some medical professionals and members of the public was that AIDS was a homosexual's disease and ignorance and prejudice dominated. By 1987 it became known that the virus had also become prevalent in the heterosexual community – particularly among blacks, and these feelings were then extended to blacks. Grundlingh asserted that 'religious objections, cultural taboos, ostrich-like complacency, xenophobia and prudishness' presented major obstacles to any HIV prevention efforts (p. 103). Phatlane (2003) explained that the Apartheid system created conditions for the growth of the epidemic through the creation of impoverished homelands, the migrant labour system, a fragmented and inefficient health care system across homelands as well as segregated health services.

Nattrass (2004) argued that the first democratically elected government that took over power in 1994 got off to slow start in addressing the epidemic, notwithstanding the problems that it inherited. The 1990s were characterized by weak high-profile, quick-fix solutions, the most notable of which was the disastrous attempt to stage Sarafina II with an anti-AIDS message that was projected to cost the government R14.2 million. Heinecken (2003) remarked that in recent years:

> ...the South African government has become embroiled in a series of AIDS controversies resulting in disunity and conflict among government and various nongovernmental organizations, the most crucial being President Mbeki' s musings as to whether there is a causal link between HIV and AIDS. The public questioning of AIDS knowledge has reinforced doubts and denial, setting back advances to bring about the necessary behavioral change to stem the epidemic. (p.295)

Nattrass (2004) asserted that "Mbeki's questioning of established scientific knowledge and best-practice medical interventions succeeded in driving a wedge between the scientific community and the government" (p. 51). Furthermore, Benatar (2004) commented:

> It has been a great disappointment that a new, enlightened democratic government could so arrogantly deny the link between HIV infection and AIDS in the face of overwhelming evidence provided by the global scientific community. (p. 88)

Many people working in the HIV/AIDS field believe that South Africa lost three years in the fight against AIDS dude to Mbeki's dalliance with denialists who question the link between HIV and AIDS (Cohen, 2004). Sadly, there have been too many indicators of a lack of commitment by the government to properly address the HIV/AIDS crisis in South Africa. Examples include: (a) a delay in allowing infected mothers to be given prophylaxis treatment to prevent transmission to their infants; (b) misappropriation of state funds for dubious HIV prevention campaigns; (c) failure to spend all the funds that were allocated in the AIDS budget; and (d) denying access to life-prolonging drugs to all those who need them (Mitton, 2000; Delius & Walker, 2002; Henderson, 2000; Schneider & Fassin, 2002; Van Niekerk, 2001). One commentator has described the slow (and inexplicable) actions of the Government as "death by dithering" ("Death by dithering", 2003, p. 67).

While there has been considerable criticism of President Mbeki's handling of the AIDS crisis in South Africa, there have been few attempts to understand or explain his actions. Sheckels (2004) challenged: "Put bluntly, what was he doing? Was he acting irresponsibly and blundering badly. Or was he acting responsibly and communicating strategically?" (p. 69).

Ncayiyana (2001), who is the editor of the South African Medical Journal, believed that Mbeki's government had "quite correctly been cautious about committing itself...to ART and other treatment programs...." (p. 1858). Ncayiyana justified his opinion by claiming that South Africa could not afford to treat every patient with AIDS even at reduced prices, and that it lacked the medical person-power and infrastructure for a successful treatment programme. Furthermore, he argued that too much emphasis was being placed on ARV treatment to the detriment of HIV prevention. This sympathetic view of Mbeki's response is certainly not shared by all South African medical professionals. Abdool Karim (2000a) argued (as have many others) that South Africa had the capability to effectively respond to the epidemic since countries with fewer resources such as Uganda have already had major success. Abdool Karim, Abdool Karim, and Baxter (2003) advocated a rational approach to controlling the epidemic insisting that the introduction of ARV treatment be accompanied by "concomitant improvements in prevention...so that AIDS deaths and new HIV-1 infections both decrease" (p. 1499).

Sheckels (2004), a language and communications specialist in the US, attempted to explain Mbeki's motives by analyzing rhetoric from various speeches he made from 1998 to 2001. He came to the conclusion that Mbeki's rhetoric on AIDS was "both sincere and politically savvy" (p. 70) and he asserted that:

> ...although Mbeki's rhetoric may have slowed some efforts to address the HIV/AIDS epidemic, the rhetoric had the potential to produce solidarity among the Black South African people and may have helped HIV/AIDS sufferers by drawing the world's attention to the different characteristics of the African epidemic and forcing the Western governments and drug companies to make their solutions more affordable to poverty-stricken African nations. (p. 71)

This sympathetic depiction of Mbeki as a shrewd politician and "not the bumbler the Western press has sometimes portrayed him as" (Sheckels, 2004, p. 80), may be difficult for some people to accept because it appears to minimizes the extent of suffering that has resulted from Mbeki's "rhetoric" and more importantly his actions (or lack thereof).

The sorry tale continues. Recently the President provoked reaction again by questioning the magnitude of mortality associated with AIDS in South Africa (Philips, 2003). In fact, a report released at the beginning of 2005 concluded that for the year 2000-2001, the number of AIDS-related deaths was likely to be almost three times as high as that published in the Government's statistical report compiled from death certificates ("South Africa needs to face", 2005). According to Nattrass (2004), excuses by the government for not dealing effectively with the AIDS crisis are no longer acceptable:

> One (increasingly tired) explanation is to point fingers at the 'inherited' bureaucracy, and blame the difficulties involved in trying to amalgamate the many apartheid bureaucracies into a more efficient system...But pointing to such difficulties as a reason for the failure to deliver an adequate public health response is credible only for so long. There is a limit to how long a government can blame its own bureaucracy without being held to account for that failure. (p. 44)

Regarding the government's inertia in providing life-saving treatment to all infected citizens, Sewpaul (2002) accused the government of betraying its citizens and abandoning them, indicating that the message that the government has communicated to those affected by the epidemic – people who are poor, unemployed, stigmatized and with little hope for the future – could be interpreted as follows: "'We don't care enough about you to save your life but please use your sense of moral responsibility and save the life of other people'" (p. 405).

Nattrass (2004) suggested that decisions about providing public access to ARV should not be in the hands of technocrats but rather be decided through public consensus. In other words, let citizens decide how they want the issue of ARV treatment addressed. Whatever decision is made, Nattrass insisted that it should be through a "...social process of deliberation. The point is that such a process is preferable to one in which social choices are made by the government and disguised as technical issues" (p. 182).

But providing ART is not cheap, and Benatar (2004) in his analysis of health care reform and AIDS in South Africa, warned that:

> Providing antiretroviral treatment to hundreds of thousands of people for many years, in addition to offering adequate integrated care for tuberculosis, malnutrition, and other associated diseases of poverty, presents major challenges in terms of cost, health care delivery, and other factors. (p. 90)

Nattrass acknowledged that the exorbitant cost of providing ARV treatment will necessitate either an increase in taxes or a shifting of resources from other spending priorities. Benatar (2004) suggested that resources could be shifted from the military budget which is the "best potential local source of additional funding" (p. 90). He indicated that raising personal income by 5% for example would not be enough.

In November 2003, the Government finally endorsed a National Treatment Plan for HIV/AIDS. The Cabinet plan committed to treating 53,000 infected people by 31 March, 2004. In the current budget more funds have been allocated for HIV/AIDS - R12,3-billion over the next three years and R166-million has been allocated to the national health department for the ARV treatment plan ("AIDS allocation grows", 2004a). At the time of writing, progress in implementing this plan has been slow and uneven across the provinces ("Roll-out or cop-out?", 2004b). While the future is more hopeful now than it has ever been for those who are affected by HIV/AIDS, there is much uncertainty. Nattrass (2004) has predicted that "...the roll-out of AIDS treatment will be dogged by chronic problems relating to costing and resource availability" (p. 56).

There is no doubt that a profound human crisis exists in South Africa. Valuable lessons have already been learned worldwide about fighting HIV/AIDS that could help guide South African policy makers, researchers, and practitioners. According to a World Bank report (The World Bank, Africa Region, 2000, p. 21), the following strategies for combating the epidemic have been shown not to be effective:

- The absence of adequate, sustained, and high level government support.
- Inadequately targeting interventions to small sections of populations at increased risk of infection and transmission.
- Withholding knowledge from young people that would protect them from infection, under the guise of "cultural and social norms".
- Targeting the vulnerable, especially women and young girls, without addressing the root causes of their vulnerability.
- Stigmatizing and marginalizing those infected and affected by this epidemic.
- Investing in expensive pilot studies that have no chance of being sustained, replicated, or expanded.

- Building plans and programs that are externally driven, based on available funding or donor interest rather than well-coordinated programs based on need and proven strategies.
- Designing programs without community involvement.

It is hard to dispute the importance of addressing the powerful social and economic forces that drive the epidemic. Phatlane (2003) suggested that we need to provide the poor with what was denied them by the Apartheid system such as clean water, adequate housing, job opportunities, free education, fair and decent health care services, and rectifying the balance of power between men and women. Gilbert and Walker (2002) concluded that:

> Following the psycho-socio-environmental model, all potential contributing elements need to be addressed simultaneously. This calls for a true interdisciplinary and multi-sectorial approach. It also requires great commitment as well as strong political will. (p. 660)

These are worthy goals indeed, but they will take a long time to achieve, and the concern is that in the meantime the virus will continue to wreak havoc on South Africa.

Conclusion

World-wide attention has focused on the HIV/AIDS epidemic on South Africa. It has the largest number of HIV-infected people in the world, and AIDS is the leading cause of death. The reasons for the spread of the epidemic are complex; a variety of historical, social, political, economic, and cultural factors interact to shape the epidemic. Those involved in HIV prevention efforts as well as those who care for people with HIV/AIDS struggle with scarce resources in an environment dominated by stigma and denial, and the situation is worsened by the government's lack of leadership in addressing issues at all levels that fuel the epidemic. Not only is it important that attention be focused on HIV-related prevention and treatment, but also on helping those left behind – those men, women and children who have lost loved ones to AIDS. Many of those bereaved by

AIDS are themselves infected with the virus and they must endure repeated losses in their lives while trying to stay alive. Before we explore what it is like to experience AIDS-related bereavement, we need to have a basic understanding of grief and bereavement in general. So, in the next chapter I describe some key issues and topics related to bereavement. In Chapter Four, I will then focus specifically on what we have learnt so far about bereavement related to AIDS.

CHAPTER 3

An Overview of Grief and Bereavement

This chapter presents an overview of key concepts, theories, and research relating to grief and bereavement. It identifies trends in the bereavement literature and examines some strengths and limitations in our knowledge of grief and bereavement. Before I begin this chapter, I would like to mention that this overview is largely the result of my own attempts (which may be judged either satisfactory or unsatisfactory) to identify some of the main trends in the literature on grief and bereavement. I say this because almost one year after completing this chapter, I discovered an important document which in fact provides a synthesis of developments in the field of bereavement and grief research as well as recommendations for enhancing grief research. The report was completed in 2003 and published in 2004 in a special issue of the journal *Death Studies* (Center for the Advancement of Health, Vol 28, pp. 491-575). It is also available online from the Center for the Advancement of Health website (www.cfah.org). It was authored by Janice Genevro, Tracy Marshall and Tess Miller and it was based on the work of a panel of 23 distinguished U.S. scholars and practitioners in the bereavement field. When I came across this report, I felt somewhat deflated, thinking that all my hard work preparing this chapter was wasted. But I decided to leave almost everything the way it was after comparing what I had written to what was contained in the report. I was pleased (and relieved) to see that several of my observations were consistent with the main findings of the report. Of course, the report was far more comprehensive and encompassing than the overview presented in this chapter. My goal was more restrained; to provide an overview of grief and bereavement (from my own perspective) that would serve as a background to my investigation of AIDS-related bereavement in South Africa, as opposed to a state-of-the-art (or science) evaluation of the entire field. Nevertheless, the report proved particularly useful in helping me formulate recommendations in Chapter Fifteen for bereavement research related to AIDS in South Africa.

Throughout this thesis, for the purposes of clarity, the terms “bereavement”, “grief” and “mourning” will conform to the definitions suggested by Stroebe, Stroebe, and Hansson (1993) as follows:

> *Bereavement* is the objective situation of having lost someone significant; *grief* is the emotional response to one's loss; and *mourning* denotes the actions and manner of expressing grief, which often reflect the mourning practices of one's culture. (p. 5)

The Western Perspective

The death of a loved one is a universal human experience and grief in whatever form is a reaction to loss in most cultures. Over the past century, a wealth of information has been gathered to describe the grieving process and how to help individuals cope better with their loss. From the outset, it must be made clear that most of the professional literature on bereavement has been written by and about those living in the West. Most of our knowledge about bereavement is derived from empirical studies and clinical work with Caucasian bereaved individuals residing in the United States, Canada, Western European countries (particularly the United Kingdom), as well as Australia. Furthermore, the bereavement literature as a whole has been dominated by research and theory drawn from the disciplines of psychiatry and psychology and to a lesser extent sociology, philosophy and other health-related fields. Social work contributions to the bereavement literature have increased in recent years especially as it relates to psychosocial issues connected with life-threatening illnesses such as cancer and AIDS. The focus of bereavement research and theory has primarily been on the individual person, and it is only recently that there has been greater acknowledgement of the need to better understand the social and cultural contexts of bereavement (Stroebe, Hansson, Stroebe & Schut, 2001; Genevro, Marshall & Miller, 2003).

Having one foot in South Africa and the other in the United States for the past 20 years, I have witnessed on a personal as well as professional level the subtle differences that can exist in bereavement perspectives across cultures. I write this review acutely aware of the limited applicability of aspects of the bereavement literature to the South African context. It is disappointing that so little attention has been paid by researchers and theorists to understanding grief, bereavement and mourning from an African perspective.

There are several books on the differences between cultures or religions in terms of beliefs and traditions about dying, death, grief, and the afterlife. One well-known book is *Ethnic Variations in Dying, Death and Grief: Diversity in Universality* by Irish, Lundquist, and Nelsen (1993) that focuses on African-Americans, Mexican-Americans, Native-Americans, the Hmong, as well as the following religions: Judaism, Buddhism, Islam, and Quakers and Unitarians. Johnson and Mcgee's (1998) book, *How Different Religions View Death & Afterlife,* presents information on death & afterlife beliefs of 19 different religions. The most comprehensive work so far has been the three volume work, *Death and Bereavement Around the World,* by John Morgan and Pittu Laungani, renowned thanatologists from Canada and the UK respectively. The first volume was published in 2002 and focused on death and bereavement across 11 major religious traditions. This was followed in 2003 by volume two which focused on death and bereavement in the Americas which included the following countries: the US, Canada, Mexico, Jamaica, Panama, Colombia, Brazil, Peru, Argentina, and Venezuela. Volume three, published in 2004, covered countries in Europe. The latest volume focuses on Asia, Australia, and New Zealand. Hopefully, the next volume will cover Africa and it is interesting that this continent has been left for last.

It is widely acknowledged that there is a huge gap in our understanding of the perspectives of different cultures as it relates to death-related phenomena, in particular grief and bereavement, and this has been identified as an important area for future research (Rosenblatt, 2001; Shapiro, 2001).

Genesis of Bereavement Theory

The professional literature on bereavement had its origins in Europe at the start of the twentieth century. In his 1917 classic paper, "Mourning and Melancholia", the psychoanalyst Freud wrote that grieving is a process during which emotional energy or libido is withdrawn from the deceased and redirected and the ego becomes free and uninhibited again (Freud, 1957). Grief theorists often neglect to mention, when referring to Freud, that he also viewed grief as a normal experience prompted by loss and that under normal circumstances most individuals would heal on their own without intervention. Freud (1957) defined grief as:

> ...the reaction to the loss of a loved person, or to the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal, and so on...It is also well worth noticing that, although mourning involves grave departures from the normal attitude of life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful. (pp. 243-244)

Stage Models

It was not until the end of the Second World War that another major work in bereavement appeared. Eric Lindemann, a psychoanalyst, published an important paper describing the reaction to bereavement, its course, as well as treatment for problems associated with bereavement. He was also the first theorist to conceptualize grief as a process involving stages. Lindemann (1944) identified three stages of grief: shock and disbelief, acute mourning, and resolution of the grief process. Shock and disbelief were characterized by an inability to accept the loss and there could be complete denial on occasion that the loss occurred. In the acute mourning stage, there was acceptance of the loss accompanied by various emotions and behaviors such as crying, feelings of loneliness, disinterest in daily life, loss of appetite, insomnia, as well as an intense preoccupation with the deceased. Resolution of grief occurred when the individual gradually resumed the activities of daily living, was interested again in life and became less preoccupied with the deceased. Lindemann coined the phrase "grief work" to describe the process of resolving grief. He saw a role for psychiatrists in helping patients with their grief work and predicted it could be done over 8-10 sessions.

In 1961, John Bowlby presented a theory of grief based on his comprehensive work on attachment formation between mother and child and the psychological reaction of small children to separation from their mothers. Bowlby (1980) suggested that grief was related to the attachment that the bereaved continued to feel toward the deceased. Attachment behavior was defined as any form of behavior that resulted in the individual striving to get close to the other individual. These behaviors would include seeking out the other individual, looking at him/her, calling out to the individual, and demanding to be closer to him/her. These behaviors were evident when an individual was grieving as well. Bowlby indicated that the grief process was divided into four successive phases: numbness, yearning and searching, disorganization and despair, and reorganization. In the phase of numbness, the bereaved is stunned and there may be varying degrees of denial that the loss occurred. In the phase of yearning and searching, there is a strong urge to locate and be reunited with the deceased. Finally, in the phase of reorganization, the bereaved loosens their attachment with the deceased and begins to establish new ties with others. Bowlby recognized that there were variations in responses to loss and that not all the bereaved went through these phases in the same way or at the same speed (Bowlby & Parkes, 1970).

A similar model was proposed by Engel (1961) who described the normal sequence of grief as follows:

- *Shock and disbelief.* The bereaved is stunned and may try to numb the pain by blocking out the loss and painful feelings.
- *Developing awareness.* Acknowledgement of the loss begins and anger, guilt, crying or self-destructive behavior may be present.
- *Restitution.* Mourning rituals such as funerals provide social support to the bereaved and stimulate the expression of emotions.
- *Resolving the loss.* The bereaved attempts to deal with the void left by the deceased, there may be preoccupation with the deceased that includes the loss experience as well as the relationship with the deceased.
- *Idealization.* Most negative and hostile feelings toward the deceased are repressed, yearning and sadness diminishes, there is acknowledgement that the deceased would want the bereaved to continue living, and interest in new relationships begins.
- *The outcome.* After a year or so, successful healing occurs and the bereaved is able to comfortably remember both the positive and disappointing aspects of the lost relationship.

Unlike his predecessors, Engel viewed grief itself as a disease because it produced various psychological and physiological symptoms, it caused a lot of mental anguish, and it impaired daily functioning. However, most bereavement scholars today believe only a minority of individuals will experience grief that can be labeled "pathological", meaning it fails to follow the course that is considered normal in Western society (Parkes, 2002).

Perhaps the most widely known and influential stage model of grief was developed by Kubler-Ross (1969) who outlined five stages an individual goes through when coping with imminent death. These stages, which have also been used to describe the grief process among the bereaved, are: *denial, anger, bargaining, depression, and acceptance of the loss*. The first phase consists of shock and denial which is considered a normal initial reaction. As the shock wears off, the individual may become angry over the lack of control over the loss and this may be followed by bargaining for the return of the deceased with promises of changes in behavior or lifestyle. When these bargaining thoughts yield nothing, hopelessness sets in and the individual may experience a period of depression, sadness, even despair. The final phase involves the individual fully accepting the loss and been capable of thinking about the deceased without the same emotional upheaval, as well as having positive thoughts about the future.

Rando (1984) concluded that although there were various conceptualizations of the grief process they all covered the same emotions, which she collapsed into three broad phases:

> Avoidance, in which there is shock, denial, and disbelief; Confrontation, a highly emotional state wherein the grief is most intense and the psychological reactions to the loss are felt most acutely; and Reestablishment, in which there is a gradual decline of the grief and the beginning of an emotional and social reentry back into the everyday world. (p. 29)

A few years later, Neimeyer (1998) offered his "own distillation of prominent psychological responses to loss" (p. 18). He delineated three phases of grief:

- Avoidance – characterized by shock, numbness, and confusion initially, followed by vivid emotions as the reality sets in, and oscillating between denying the reality of the death and being overcome by grief and anguish the next moment.
- Assimilation – characterized by intense loneliness and sorrow, withdrawal from the larger social world, depression, crying spells, prolonged stress and anxiety, disturbances in sleeping and eating, physical complaints, and hopelessness about the future.
- Accommodation – characterized by resigned acceptance of the reality of the loss, lessening of physical symptoms, greater sense of control of emotions, rebuilding ties with the social world, and a continued balancing act of remembering the past and reinvesting in the future. (p. 18)

Tasks of Grief

The implication of stage models of grief is that the bereaved individual must wait because "time heals all wounds". A number of theorists and clinicians have challenged the underlying assumption that grief is a passive process and have advocated a perspective of grief as an active process of accomplishing certain tasks that will help individuals adjust to their loss. One early model by Parkes and Weiss (1983) proposed that the bereaved need to accomplish the following three tasks in order to recover from grief:

- *Intellectual recognition and explanation of the loss.* The bereaved must recognize and be able to explain how the loss occurred to avoid further anxiety.
- *Emotional acceptance of the loss.* Through constant review of memories, thoughts, and feelings, the bereaved reaches a point where the reminders of the loss are not too painful.
- *Assumption of a new identity.* Gradually, the bereaved adjusts to an altered life situation and develops a new identity.

Worden (1991) built on the perspective that there were things that the bereaved could do to facilitate their adjustment to loss. He outlined four *tasks* of grieving that need to be accomplished before grief is complete. These tasks are to: accept the reality of the loss, experience the pain of grief, adjust to an environment in which the deceased is missing, and withdraw emotional energy and reinvest it in another relationship. Parkes (2002) remarked that this model of tasks of grieving was helpful for counselors because of its practical implications. Attig (1996) similarly endorsed the view that while bereavement (the situation of having lost a loved one) was choiceless, grief or the way an individual responds to loss was not choiceless. Attig proposed that: "grieving as coping requires that we respond actively, invest energy, and address tasks" (p. 33). However, he was not so enamoured of Worden's "tasks" and argued that they were not so much tasks but principles of coping. Attig explained that Worden's "tasks" "...are not rigourously defined, they are not circumscribable, modest in scale, or completable" (p. 49). Attig proposed that grieving was a process of relearning the world:

> Viewing grieving as relearning gives specific content to the active, task-based idea of grieving and defines the range of activities involved...we learn how to be and act in the world that is transformed by our losses. We reshape all facets of our lives...When we grieve, we must relearn virtually every object, place, event, relationships with others, and aspects of ourselves that the lives of those who have died have touched. Our grieving takes as long as it does because there is so much we must relearn. (p. 122)

Attig's assumption was that loss challenges us to relearn things and places, relationships with others including the deceased and God, elements of our daily routine, and the meaning of our own life. We must relearn how to be ourselves in a world that has been changed as a result of our loss and typical tasks include deciding when to return to work, choosing to move, deciding to return to an activity that the deceased introduced into one' life, and deciding who to interact with and how often. Neimeyer (1998) subsequently reformulated these tasks as "challenges". He reiterated that these challenges were not accomplished in any particular order nor are they ever completely over. The challenges are: acknowledging the reality of the loss, opening oneself up to the pain, revising one's assumptions about the world, reconstructing one's relationship to the deceased, and rebuilding one's identity.

Cognitive Stress and Coping Theory

The cognitive model of stress and coping of Lazarus and Folkman (1984) has been used widely in research on bereavement (Lund & Caserta, 1998; Kato & Mann, 1999; Meuser & Marwitt, 1999; Folkman, Chesney, Collette, Boccellari, & Cooke, 1996; Goldblum & Erickson, 1999; Stein, Folkman, Trabasso, & Richards, 1997). According to this framework, a situation (e.g. the loss of a loved one) is considered stressful when it is "appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). The two key concepts in stress and coping theory are *appraisal* and *coping*. Appraisal refers to the perception that the individual is in danger as well as the perceived availability of resources for managing potential or actual harm. Coping refers to the process whereby the individual adopts certain responses to manage the demands that are appraised as stressful. In effective coping, the individual determines what form of coping is appropriate to deal with the stressful situation and then competently applies this form of coping (Goldberger, & Breznitz, 1982). There are two main types of coping: problem-focused coping which involves managing or changing the problem causing distress, and emotion-focused coping which involves regulating one's emotional responses to the problem (Lazarus and Folkman, 1984).

Folkman et al. (1996) applied the cognitive framework of stress and coping to their study of AIDS-related bereavement among gay men in San Francisco and they hypothesized that the impact of bereavement on the person would be:

> ...influenced by the personal and social resources the person has available for coping and by the various types of emotion-focused and problem-focused coping that he uses to manage the emotional and instrumental demands of the events. (p. 3)

Data from this important study, known as the University of California, San Francisco (UCSF) Coping Project, has been published in several articles. The cognitive stress and coping model offers an alternative view of bereavement from traditional theories that assert that the death of a loved one must be confronted and worked through. The main emphasis is on the bereaved individual's "subjective evaluations of the difficulties surrounding the loss" (Bonanno & Kaltman, 1999, p. 5). An implication of this perspective, which contrasts with the grief work assumption, is that choosing avoidant coping (i.e. not dealing directly with the problem) can sometimes be helpful to the bereaved (Bonanno, Keltner, Holen, & Horowitz, 1995).

Grief as a Dual Process

Rubin (1999) noted that two approaches underlie most of the literature relating to loss. One approach focuses on the difficulty of working through the loss, particularly as it relates to separation from the deceased and changes or weakening in ties to the deceased. The other approach focuses on the biological, behavioral, cognitive, and emotional effects or outcomes of bereavement. He saw a need to combine the two and so he proposed a "bifocal approach to bereavement". His two-track model of bereavement addresses both the bereavement process and its outcome. Track I focuses on the biopsychosocial reactions to loss and Track II focuses on how the bereaved maintain and change their relationships to the deceased.

Stroebe and Schut (1999) recognized the value of this model in identifying dual dimensions of loss – daily functioning and relationship to the deceased – but they criticized it for not focusing on the coping process itself. As a result, they proposed a dual process model of coping with bereavement (Stroebe, 1998; Stroebe & Schut, 1999). In their view, the bereaved "oscillate" between two types of coping: loss-oriented coping and restoration-oriented coping. This means that there are times when the bereaved will be focused on thoughts of the loss (e.g., yearning for the deceased, crying, examining old photos, or imagining things that the deceased might say) – loss-oriented coping. It is also appropriate at times to put aside one's grief, adjust to changes and make plans for the future (e.g. finances, selling one's house, or developing a new identity from husband to widower) – restoration-oriented coping. According to Stroebe (1998), "there may be different reasons why, at any particular point in time, a bereaved person will be loss- or restoration-oriented..." (p. 11).

Manifestations of Normal Grief

Worden (1991, pp. 22-30) identified a range of normal grief behaviors which he placed into four categories: (1) feelings; (2) physical sensations; (3) cognitions; and (4) behaviors. These categories are outlined in Table 3.1. Worden indicated that if any of these grief manifestations exist for "abnormally long periods of time and at excessive intensity", this may signify complicated grieving - which I will describe shortly.

Table 3.1 Manifestations of normal grief

Feelings	Physical sensations	Cognitions	Behaviors
-Sadness -Anger -Guilt & self-reproach -Anxiety -Loneliness -Fatigue -Helplessness -Shock -Yearning -Relief -Numbness	-Hollowness in the stomach -Tightness in the chest and/or throat -Extreme sensitivity to noise -Feeling not real -Shortness of breath -Weakness -Lack of energy -Dry mouth	-Disbelief -Confusion -Preoccupied with the deceased -Sensing the deceased is still present -Hallucinations	-Sleep disturbances -Appetite disturbances -Absent-minded behavior -Social withdrawal -Dreams of the deceased -Avoiding reminders of the deceased -Searching/calling out -Sighing -Restlessness -Crying -Visiting places that remind one of the deceased -Treasuring objects that belonged to the deceased

Factors Influencing Grief

There is widespread agreement that each person's grief is unique, determined by a combination of psychological, social and physiological factors. Rando (1984, pp. 43-57) and Worden (1991, pp. 32-34) described common factors that influence grief which I have outlined in Table 3.2:

Table 3.2 Factors that influence grief

Individual factors: - Age - Coping behaviors - Personality/mental health - The way the loss is viewed. - Past experiences with loss - Socioeconomic status - Alcohol and other drugs - Physical health (nutrition, rest and sleep, exercise)	Stresses - Number, type and intensity of stresses before the death - Presence of concurrent stresses unrelated to the death - Secondary losses after death (loss of status, finances)	Social factors - Social support system - Sex-role conditioning - Social, cultural, ethnic, religious background
The deceased - Age - Type of person he/she was - Roles occupied in the family or social system	Relationship with deceased - The strength of the attachment with the deceased and qualities of the relationship lost. - Amount of unfinished business between the bereaved and the deceased - Perception that the deceased had a fulfilling life	The death itself - Location, type of death, reason for death - Sudden versus expected death - Length of illness before death - Timeliness of death - Feelings about whether the death could have been prevented

Anticipatory Grief

The term "anticipatory grief" was first introduced by Lindemann (1944) and there has been considerable discussion about its relevance over the years (Rando, 1984). It refers to grief responses in anticipation of a future loss, which typically occur between the diagnosis of a life-threatening illness and the death of the individual (Walker, Pomeroy, McNeil, & Franklin, 1996). Anticipatory grief includes feelings of sadness, anxiety and depression, increased concern for the terminally ill person, the struggle to come to terms with the impending death of the person and its consequences, changing assumptions about life and their identity, and making plans for the future without the deceased

(Rando, 1984). The evidence is mixed as to whether the opportunity to grieve before a death affects the bereavement process by preparing the survivor for the death, or lessens the length of bereavement or reduces the physical and mental impact of the loss (Stroebe & Stroebe, 1993a).

Nord (1997) argued that the term "anticipatory grief" serves no purpose and in fact could be harmful. He suggested that classifying grief as either predeath grief or post-death grief is "artificial and inaccurate" and "to divide genuine grief from anticipatory grief overtly minimizes the survivor's experiences" (p. 88). I don't believe that is the underlying assumption or intention of this concept and I agree with Rando's (1984) suggestion that "anticipatory grief be recognized as a legitimate phenomenon" (p. 40). What is important to remember is that individuals may experience a host of reactions in anticipation of the death of a loved one and we need to be sensitive to this. Arguing about whether this phenomenon makes adjustment after the death easier or harder does not have much practical value.

Complicated Grief

Grief is not an illness and it is important not to "pathologize" it as such. As the report of the Center for the Advancement of Health states, "the majority of the population appears to cope effectively with bereavement-related distress, and most people do not experience problematic grief or adverse bereavement-related health effects" (Genevro, Marshall, & Miller, 2003, p. 10). However, there are times when an individual may become "stuck" in the grief process, for example when the loss is a traumatic one (e.g. homicide, death of a child, multiple losses due to AIDS). Over the years, a number of theorists and researchers have attempted to describe the phenomenon of complicated grief and there has been much confusion over the proper term to use (e.g. complicated grief, pathological grief, or complicated mourning) (Middleton, Moylan, Raphael, Burnett, & Martinek, 1993; Goldblum & Erickson, 1999) as well as how to assess and classify it (Genevro, Marshall, & Miller, 2003). There has been much overlapping in the identification and classification of abnormal or pathological grief reactions (Lindemann, 1944; Lazare, 1979; Parkes, 1965; Parkes & Weiss, 1983; Bowlby, 1980; Worden, 1991). According to Middleton et al. (1993):

> Pathological grief is not represented in official diagnostic manuals. Nor is it an established "clinical entity"... [and] there is considerable overlap with other, more operationally defined syndromes, such as depression, anxiety, or post-traumatic stress disorder. (p. 59)

I prefer to use the term "complicated grief" and I will use this term throughout when referring to this phenomenon. A widely cited definition of complicated grief is by Horowitz, Wilner, Marmar, and Krupnick (1980) who defined it as:

> the intensification of grief to the level where the person is overwhelmed, resorts to maladaptive behavior, or remains interminably in the state of grief without progression of the mourning process towards completion...[It] involves processes that do not move progressively toward assimilation or accommodation but, instead, lead to stereotyped repetitions or extensive interruptions of healing. (p. 1157)

On the other hand, Goldblum and Erickson (1999) simply defined complicated grief as "an atypical intensity or duration of grief symptoms that leads to a level of functional impairment in critical areas of work and relationships" (p. 2). Worden's (1991) perspective of complicated grief is one that is commonly referred to by researchers and practitioners in the bereavement field today. He identified four types of complicated grief reactions: chronic grief, delayed grief, exaggerated grief, and masked grief. Chronic grief is when the grief is excessive in duration and does not come to a satisfactory conclusion. Individuals experiencing this type of reaction are usually aware that they are not moving through the grief process. Delayed grief is when the individual has an emotional reaction at the time of the loss, but it is insufficient. The individual may feel so overwhelmed at the time of the loss, that it causes their grief to be delayed. When a later loss occurs, the grief is triggered and the individual's response will be more intense and exaggerated compared to the past loss. Exaggerated grief has to do with excessive and disabling reactions to loss and psychiatric disorders develop following the loss such as clinical depression, anxiety, alcoholism, and post-traumatic stress disorder. Usually, the individual is aware that his/her response is abnormal and will seek help. In masked grief, the individual will experience symptoms and behaviors that will cause them difficulty but they are not aware that they are related to the loss. In masked grief, the grief shows up masked as a physical symptom or as some type of aberrant or maladaptive behavior. The individual may experience physical symptoms that were similar to those of the deceased before he/she died (Worden, 1991).

Symptoms of Complicated Grief

Bereavement interventions are usually not needed for individuals experiencing normal grief but they may be helpful for "a small, though significant, percentage of the population [who] experiences complicated grief" (Genevro, Marshall & Miller, 2003, p. 10). Robert Neimeyer (1998), a clinical psychologist and renowned bereavement scholar in the United States, indicated that professional counseling may be required for bereaved individuals who experience any of the following conditions on a continual basis: substantial guilt, suicidal thoughts, extreme hopelessness, prolonged agitation or depression, physical symptoms (e.g., stabbing chest pain or extreme weight loss), uncontrolled rage, persistent impairment in everyday functioning (e.g. job, daily living tasks), and substance abuse.

The following are symptoms of complicated grief, adapted from Lindemann (1944), Lazare (1979) and Worden (1991):

- The person develops physical symptoms similar to those of the deceased before death.
- Panic attacks, choking sensations, and shortness of breath.
- Searching behavior that continues over time.
- Extreme anger directed toward those involved at the time of death (e.g. doctor, nurse).
- Lack of emotion.
- Agitated depression, feelings of worthlessness, and persistent guilt.
- A feeling that the death occurred yesterday, even though it was months or years ago.

- An inability to talk about the deceased without experiencing fresh and intense grief even when the death occurred over a year ago.
- Unaccountable sadness occurring at a certain time each year.
- A minor event triggers a major grief reaction.
- False euphoria subsequent to the death.
- Radical changes in lifestyle.
- Acting in a way that can be detrimental to one's social and economic existence (e.g. making foolish economic decisions, giving away things).
- Unable to move the possessions of the deceased after a reasonable time has passed and preserving the environment exactly as it was at the time of death.
- Refusing to participate in mourning rituals such as attending the funeral or visiting the grave.
- A compulsion to imitate the dead person's behavior.
- Phobias that one will develop the illness that took the deceased.
- Changes in relationships with friends and family.
- Excluding friends, family, or activities connected with the deceased.

Causes of Complicated Grief

Neimeyer (1998) identified factors that could result in complicated grieving. They are: characteristics of the bereaved individual (e.g. use of maladaptive coping strategies such as alcohol and drug use); level of support available to the bereaved individual; and "bereavement overload" (when the individual is confronted by multiple deaths in a certain time period such as individuals who have lost many of their loved ones to AIDS). Neimeyer suggested that the most significant risk factor for complicated grieving is whether the individual had difficulty coping in the past with similar major losses.

Table 3.3 summarizes risk factors for complicated grief, adapted from the work of several authors (Lazare, 1979; Parkes & Weiss, 1983; Worden, 1991; Gamino, Sewell, & Easterling, 2000; Parkes, 2002). I have adopted Worden's classification system. He categorized risk factors for complicated grief as: relational factors (aspects associated with the relationship with the deceased); circumstantial factors (circumstances surrounding the loss); historical factors (prior losses); and personality factors (aspects of the person's character).

Table 3.3 Risk factors for complicated grief

Relational factors

- Ambivalent toward the deceased
- Highly dependent on the deceased
- The deceased represents an extension of oneself
- Lost opportunities to have a certain type of relationship

Circumstantial factors

- Loss is uncertain (e.g. when the body is not found)
- Sudden or unexpected losses
- Traumatic death (violent or horrific losses)
- Multiple losses
- Losses for which the person feels responsible
- Losses where others are to blame
- Disenfranchised losses (i.e. losses that are not acknowledged by society)

Historical factors

- Previous history of complicated grief reactions
- Early parental loss
- Poor or insecure attachments to parents during childhood
- History of mental health treatment

Personality factors

- Unable to tolerate emotional distress
- Unable to tolerate feeling helpless
- Feeling that one needs to be "strong" for the family

Social factors

- The loss is "unspeakable" (e.g. suicide, AIDS)
- The loss is negated (e.g. miscarriage)
- Absence of social support
- Social isolation

Disenfranchised Grief

Doka (1989) proposed the concept of "disenfranchised grief" which he defined as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (p. 4). He suggested that grief could be disenfranchised in three main ways: the relationship is not recognized; the loss is not recognized; and the griever is not recognized. These are briefly discussed.

There is the assumption that close relationships only exist between spouses and immediate kin. Other types of relationships (e.g. friends, lovers, neighbours, coworkers, roommates) are not recognized for their closeness and consequently, the grief of these individuals may not be acknowledged or socially supported. Even those who had a relationship with the deceased in the past, such as ex-spouses, former friends or co-workers, may experience grief but this will not be acknowledged by society. Individuals who were involved in a relationship with the deceased that was not publicly recognized or socially sanctioned (e.g. cohabitation, same sex relationship, extramarital affair) will experience little social support for their grief. Then there are situations where grief is not acknowledged based on the characteristics of the bereaved individual. Examples are young children, the very old, and the mentally disabled. The sense of loss and need to mourn is not acknowledged for these individuals.

Certain types of losses may be viewed as insignificant and not deserving of social support. Examples include abortion, giving up a child for adoption, and the death of a pet. Certain types of death may also be "disenfranchising" such as those involving AIDS or suicide (Doka, 1989). Society may turn away from these types of deaths because of the high stigma attached to them and because the complexities of these deaths are not well understood (Corr, 1999). Many of the emotions typically associated with normal grief (e.g. sadness, depression, anger, hopelessness, numbness) are intensified, and this occurs in a social context where the bereaved individual is not accorded the right to grieve or mourn. For example, the bereaved may be forbidden to play an active role in caring for the dying person or be excluded from attending the funeral (Doka, 1989). It is important to note that different societies have different views about different types of death and a death that is disenfranchised in one society may not be disenfranchised in another society

Controversial Issues

In the past few years, "the bereavement field has witnessed considerable conceptual and empirical ferment" (Bonanno & Kaltman, 1999, p. 760). I have identified several issues that have dominated the bereavement field in the past few years as well as areas that have been problematic.

Grief as Work

There has been growing dissatisfaction with traditional models of grief and there have been challenges to mainstream thinking about bereavement. One controversial debate has been about the "grief work" hypothesis which posits that it is absolutely necessary for every bereaved individual to work through his or her grief in order to adjust to loss. Wortman and Silver (1989) argued that grief work may actually have detrimental consequences. In response, Stroebe, van den Bout, and Schut (1994) asserted that while there was little empirical support of the benefits of grief work, they did not agree with the interpretation that grief work was detrimental to the bereaved. Rather, "some times, for some people, in some situations, working through grief may neither be necessary nor better than non-confrontational or even avoidance strategies" (Stroebe, 1992, p. 37).

Lindstrom (2002) proposed a moderate approach which seems to make sense; that we should not pressure the bereaved to work through their loss nor should we tell them to totally avoid it. Rather, we should:

> ...tell people to accept their emotional and cognitive reactions in a very simple and relaxed way: recognize them and let them pass without trying to push them away in an obsessive manner. We should reassure them that the simple passage of time usually has a dampening effect on any emotions and a healing effect on any wound...Then, we should recommend the bereaved to get involved in (ordinary) life as soon as they can manage. (p. 19)

Stage Models

There has been a proliferation of models encompassing stages or phases of grief, but in recent years there has been a shift away from this formulation of grief primarily because there has been very little empirical support for the universal presence of stages that bereaved individuals must follow in response to loss (Wortman & Silver, 1989; Neimeyer, 1998). Many of those who work with the bereaved feel that it is inappropriate to impose this type of model on their clients and believe that individuals must be allowed to grieve in their own way and own time. One of the reasons for the popularity of this perspective is its ability to "simplify and compartmentalize what in essence is a diverse and complex series of enormously powerful emotions" (Sherr, 1995, p. 2). But a consequence is that bereaved individuals may be left with the feeling that something is wrong with them due to the wide gulf between their experience of grief itself and widely held assumptions about the grief process.

The Role of Context

There is consensus in the bereavement literature that the context plays an important role in influencing the bereaved individual's response to loss (Stroebe & Schut, 1999; Klass, 1999; Neimeyer, 1998). But the bereavement literature has narrowed the study of contextual factors to "a relatively finite set, including age, gender, income level, type and expectedness of the loss, previous experiences with loss or depression, and perceived social support" (Bonanno & Kaltman, 1999, p. 13). In reality, there have been relatively few empirical studies that have explored the interaction of other contextual factors on bereavement.

Bonanno and Kaltman noted that "cultural influence is a significant, but grossly understudied, factor in bereavement" (p. 14). Most traditional models of grief have limited application to different cultures (Stroebe, 1992; Klass, 1999). As Rosenblatt (1993) noted, "there is such a wide range of culturally appropriate expressions of grief across cultures" (p. 104). We need to view grief within a cultural framework and studies that compare cultural similarities and differences will greatly enhance our understanding of bereavement (Lund & Caserta, 1998). According to Klass (1999), bereavement interventions will only be effective if they incorporate the influence of culture on grieving and the bereaved individual's cultural understanding of death. Similarly, Stroebe, Hansson and Stroebe (1993) indicated that cultural factors have not been adequately understood, particularly in relation to complicated grief. They called for more systematic, scientific studies of different patterns of reactions to loss across cultures, in particular "research that goes beyond the charting of mourning rites and rituals by anthropologists and ethnographers, on which so much of our knowledge has had to rely so far" (p. 464). Klass (1999) added that we need to pay more attention to involving those who have little voice in the formulation of bereavement models as well as consider how political and economic interests influence the individual bereavement experience. This is a crucial point.

Gap between Research and Practice

Wolfe and Jordan (2000, p. 569), clinicians in Minnesota and Boston who work with bereaved individuals, argued that they and other clinicians often felt like bereavement researchers were from some "other planet", and they questioned how helpful bereavement research was in "the real clinical world". One of their grievances was the lack of empirically supported "coherent theory" as well as the scarcity of empirically validated techniques to facilitate the grief process. These limitations have in fact been acknowledged by leading bereavement researchers (Stroebe, van den Bout, & Schut, 1994). Grief counselors have developed a number of techniques to aid the bereaved, such as art therapy, creation of personalized rituals, bibliotherapy, keeping a journal, and support groups. Yet, with the exception of support groups, there has been little research on these techniques. Wolfe and Jordan asserted that there was a great need to evaluate grief counseling techniques that are commonly used in order to determine for whom and under what circumstances they are most likely to be helpful.

But even if these studies existed, this would not solve the dilemma for clinicians. As Wolfe & Jordan (2000) explained:

> ...most health care delivery organizations push staff to deliver more service rather than stay abreast of research and theoretical developments in the field. Keeping up with the multitude of journals in thanatology,

> continuing our education at workshops and conferences, trying out newly developed techniques, even participating in research activities, all seem to be lost in the press to generate revenue...In short, there are few incentives in the current system for harried caregivers to stay informed, let alone improve the quality of care by integrating new findings and empirically supported techniques into their practice. (p. 583)

The challenge of better aligning bereavement and grief research and practice was acknowledged in the Center for the Advancement of Science report on grief and it recommended more ongoing dialogue between researchers, practitioners as well as bereaved individuals (Genevro, Marshall & Miller, 2003).

Confusion over Basic Assumptions

Wortman and Silver (1989) identified common assumptions concerning the grief process that are prevalent in the bereavement literature but which are not supported by empirical work. They are as follows: the expectation that distress and depression are inevitable in bereavement, that failure to experience distress is indicative of pathology, that it is necessary to "work through" the loss, and that recovery and resolution are to be expected following loss. Stroebe, van den Bout and Schut (1994) took great exception to Wortman and Silver's position, accusing them of misinterpreting the literature and misrepresenting clinical and research contributions to the bereavement field. In their counterargument, Stroebe, van den Bout and Schut (1994) concluded the following:

- There is little evidence that bereavement researchers believe that distress or depression is inevitable. There is agreement that while most of the bereaved are distressed for weeks and months following the loss, only a small number suffer from extreme depression.
- Researchers and clinicians have not unconditionally accepted the notion that if a bereaved individual does not show distress, this is assumed to be pathological. Actually, there may be different reasons why some individuals may not show distress, including cultural norms that govern expression of grief.

- While it is true that the benefits of grief work have not been empirically supported, it is not accurate to suggest that studies have shown that working through grief can actually have the opposite effect and be detrimental.
- It is also not accurate to state that researchers assume that the grief process is something that is resolved. Whenever the label has been used it is meant to imply that the bereaved have not got over their grief, but rather used to it. The grief process is never really completed or resolved and it may be best to avoid using this label in the future. Researchers also acknowledge individual differences in how long it takes individuals to grieve and are reluctant to put a time limit on the duration of grief.

It should be pointed out that the use of certain terminology in the bereavement field has also been a bit problematic. An example of this was provided by Corr and Doka (2001), both renowned figures in the bereavement field, who debated the issue: should responses to grief be called "coping processes" or "adaptive strategies"? Needless to say, no agreement was reached about which concept should be adopted by the field, and there continues to be a lack of consensus in the bereavement field about such basic terms as "grief", "bereavement" and "mourning", which causes confusion for everyone involved, from theorists and researchers to grief counselors and lay persons (Goldblum & Erickson, 1999; Stroebe, Stroebe & Hansson, 1993). The concept "recovery following bereavement" has also been the subject of debate among bereavement researchers and in recent years its usage has fallen out of vogue. In response to critics who argue that the concept portrays bereavement as pathological, Balk (2004) suggested that while the person who died cannot be brought back and the bereaved person might not return to how he or she was before the death, the concept is appropriate when viewed as a process of personal growth and resiliency. He continued:

> Recovery following bereavement is the outcome of an active engagement with the central disruptions to one's existence. We can mature, become more attuned and empathetic to the sufferings of others, reach out to do what we can in framing new relationships with others, the world, and

> ourselves. In this complex – but paradoxically simple – sense, we recover following bereavement...(p. 372).

Despite enormous progress in the past fifty years, it is clear that the bereavement field is still evolving, and it is important to remind ourselves that we need to exercise caution when attempting to conceptualize complex phenomena. In particular, we should be wary of bold prescriptions of the best way for individuals to cope with loss.

Methodological Considerations

Like any other field of inquiry, there is a great deal of variability in the quality of empirical research on bereavement. There is certainly a need for more scientifically rigorous assessment of bereavement phenomena (Hansson, Carpenter & Fairchild, 1993). Suggestions were offered by Lund and Caserta (1998) for improving the quality of bereavement studies including: using both theory and clinical practice to help guide the research process; more controlled randomized studies to determine the effectiveness of bereavement interventions; greater use of longitudinal designs as "bereavement is a process and not just a single event in time" (p. 293); more representative samples with less reliance on clinical populations (e.g. patients or clients); and more studies "focusing on special populations where the bereavement process and its consequences are contextually imbedded in unique circumstances" (p. 295). This would include studies of disenfranchised grievers such as those who have lost loved ones to AIDS or homicide.

Neimeyer and Hogan (2001) commented that even though there are more than 2000 books and articles devoted to grief, the quality of the information has suffered due to weaknesses in measures used to study grief. In light of the fact that no gold standard yet exists in the measurement of grief, the authors offered several recommendations which are summarized as follows:

- Studies should view bereavement not only as a psychopathological process but there needs to be a broader assessment of bereavement that includes social relationships, health status, relationship to the deceased person, meaning reconstruction and identity transformation.

- More serious attention needs to be given to demonstrating the reliability and validity of scales.
- There needs to be more comparison between new instruments and existing measures.
- Researchers tend to work in small groups and ignore each other's work, so there needs to be greater collaboration and less "territoriality" between researchers.
- There is a tendency to apply scales too quickly without spending enough time on instrument development.
- Researchers need to consider using both qualitative and quantitative methods "in the same research program" instead of operating exclusively in one paradigm (quantitative or qualitative).

Because the nature of my study was qualitative, I was particularly interested in Neimeyer and Hogan's comments about this form of enquiry in bereavement research. They asserted that qualitative studies "are ideally suited to reveal the unique meanings that inform the reactions of individuals or cultural groups to death and loss, thereby broadening and deepening the scholarly study of bereavement" (p. 110). They added that such studies can "paint a picture of bereavement that is far more complex and less tidy than that suggested by the artificially amplified and controlled canvasses of quantitative questionnaires" (p. 113). But just like quantitative approaches, they warned that these studies have their own limitations and researchers in this domain must adhere to their own standards of reliability and validity, for example as outlined by Strauss & Corbin (1998).

An important issue facing bereavement researchers is how to deal with ethical dilemmas associated with collecting data from vulnerable populations and it is best summarized by this question: "How can the researcher best protect participants from the possibility of research-induced distress while also generating data that can be used to provide high quality and appropriate care in the future?" (Genevro, Marshall & Miller, 2003).

Recent Developments

In recent years, several new theoretical perspectives of bereavement have evolved and I have identified three that have been greeted with interest and have potential for broadening our interpretations of bereavement. They are the concepts of meaning reconstruction, continuing bonds, and personal growth.

Meaning Reconstruction

Neimeyer (1998) developed a way of viewing grief as "meaning reconstruction" and this has been widely discussed in the bereavement field. However, few empirical studies have been conducted so far to validate this perspective. Nevertheless, this perspective is worthy of attention since it was developed in response to the limitations inherent in traditional models of grief. According to Neimeyer, the central process in grieving is the attempt to reconstruct a world of meaning. Basically, loss requires us to reconstruct a world that makes sense, "that restores a semblance of meaning, direction, and interpretability to a life that is forever transformed" (p. 92). This perspective builds on Attig's (1996) concept of "relearning the world" (p. 99). Neimeyer has described a variety of methods to help the bereaved gain perspective on their loss including drawing and painting, keeping a journal, completing a biography of the deceased, unsent letters, and constructing a memory book which is like a scrapbook that captures thoughts, feelings, and experiences connected to the deceased.

Continuing Bonds

In their popular book, *Continuing Bonds: New Understandings of Grief,* Klass, Silverman, and Nickman (1996) shed light again on the value of continued attachment to the deceased which had been discussed a while back by Bowlby (1980). Their central premise was that "the bereaved remain involved and connected to the deceased, and...the bereaved actively construct an inner representation of the deceased that is part of the normal grieving process" (Klass, Silverman, and Nickman, 1996, p. 16). In other words, bereaved individuals do not have to relinquish their connection with the deceased but can maintain a symbolic relationship with the deceased. As Neimeyer (1998) noted:

> ...it is perhaps more accurate to say that death transforms relationships, rather than ending them. What seems necessary is not so much distancing from memories of the loved one, but embracing them, and changing the relationship from one based on physical presence to symbolic connection. (p. 45)

Several studies in the US have supported the continuing bonds hypothesis. For example, Shuchter and Zisook (1993) reported that the majority of widows and widowers during the first few months of bereavement still felt that their deceased spouses were with them at times and that they were watching out for them. Field, Gal-Oz, and Bonnano (2003) took research in this area one step further by examining continuing bonds and adjustment five years after the death of a spouse. They could draw no definite conclusions, however, about whether various expressions of continuing bonds (as measured by the Continuing Bonds Scale) were related to long-term adjustment to bereavement.

Personal Growth

It can be a challenge keeping track of the plethora of models that seem to surface in the bereavement literature. What is encouraging though is that there appears to be a greater expectation that models and concepts be empirically supported. Two recent models recognize the role of positive emotions and personal growth in bereavement. The first model is called the experiential model of bereavement developed by Hogan, Morse, and Tason (1996) based on qualitative data from thirty-four bereaved adults. They discovered that once the acute pain of grief had subsided, participants engaged in profound introspection resulting in personal growth. Participants believed they had grown more caring and compassionate and less judgmental as they reassessed what was truly meaningful in their life. This new personal growth included the recognition that life was precious and there was a reassigning of priorities.

Gamino, Sewell, and Easterling (2000) formulated an adaptive model of grief based on a quantitative study of 85 bereaved adults. The main tenet of this model is that we need to not only look at why some individuals find grieving to be more difficult than others but we need to understand better why some grieving individuals appear to adapt well despite difficulties. The authors identified four behavioral correlates of adaptive grieving: ability to see some good resulting from the death, having a chance to say goodbye, intrinsic spirituality, and spontaneous positive memories of the deceased. Gamino, Sewell, and Easterling asserted that these findings present exciting possibilities for clinicians:

> ...knowing the benefit of seeing a good result from the death opens the door to a broad range of reframing techniques within the psychotherapeutic dialogue. Assisting the mourner in recasting his/her story of death and loss to include the dimension of positive outcomes (in addition to sorrowful ones) could have highly salutary effects on the mourner's emotional state and global sense of well-being. (p. 13)

Further research needs to be done to understand what role personal growth plays in bereavement (Hogan, Morse & Tason, 1996). This has been echoed by Schaefer and Moos (2001) who asserted that we need a better understanding of "how, when, and why personal growth occurs in bereaved individuals, families, and communities" (p. 162).

Conclusion

The loss of a loved one is a very stressful experience and can at times lead to psychological and/or medical morbidity. The intensity of the grief reaction varies from person to person and between cultures. Bereavement may be prolonged or it may be of a short duration. It is important that providers and the bereaved be educated about what constitutes a normal response to loss as well as the diverse forms that grief may take. The notion of disenfranchised grief is particularly important with respect to people who have lost loved ones to AIDS. Individuals who grieve losses that are stigmatized are susceptible to grief-related problems. More research is needed to better understand cultural influences on bereavement. A critical shortcoming of the literature is its narrow focus on bereavement within North American and Western European contexts. We know remarkably little about grief and bereavement within the African context other than from anthropological studies. Finally, there is greater acknowledgment that while losing a loved one can be a painful and traumatic experience, it can also be an opportunity for personal growth and development and a chance to reveal strengths and hidden resources. In the next chapter, I focus specifically on bereavement associated with AIDS and review the research that has been conducted in this area.

CHAPTER 4

AIDS-Related Bereavement

People who die of AIDS leave behind loved ones who mourn their loss, and bereavement due to AIDS may be more difficult than bereavement associated with other types of deaths. In this chapter, we explore factors associated with AIDS that may make the bereavement process more challenging for survivors.

Applying Findings from Different Contexts

A body of research has evolved on the subject of AIDS-related bereavement. Since the late 1980s, a number of empirical studies have investigated the bereavement experiences of those who have lost loved ones to AIDS. Most of this research has been conducted in the US and has focused on gay men since they have been the population group most affected by the AIDS epidemic in the U.S and other developed countries (Martin, 1988; Kemeny & Dean, 1995; Martin & Dean, 1993a; Summers et al., 1995). With regard to South Africa, however, there has been scant information in the professional literature about AIDS-related bereavement, despite the high number of deaths in this country resulting from AIDS (Demmer, 2004a). There have also been few scholarly studies on AIDS-related bereavement from an African perspective (Kilonzo & Hogan, 1999; Nzioka, 2000; Williams & Tumwekwase, 2001; Dayton & Ainsworth, 2004). Furthermore, though much media attention has focused on the plight of children orphaned on account of AIDS in Africa (Guest, 2001; Loening-Voysey, 2002), there is still remarkably little empirical research on the bereavement experiences of these children (Bray, 2003; Wild, 2001; Children's Institute of the University of Cape Town, 2002).

In his review of the literature on the impact of HIV/AIDS on mental health, Freeman (2004) drew attention to an important question: how do we extrapolate all that has been written in developed countries to South Africa and other developing countries? He argued that we need to be critical and cautious because there are huge differences between dealing with a disease in a European or North American context and an epidemic in Africa. Freeman (2004, pp. 142-145) asserted that we should keep in mind the following important differences when applying AIDS research and practice guidelines to the local context: First, HIV/AIDS affects less than 1% of the US population compared to 11.4% of the South African population (UNAIDS, 2004; Shisana & Simbayi, 2002). Second, unlike developed countries where there is an abundant supply of mental health professionals to assist with HIV/AIDS-related mental health problems, there is a much smaller proportion of such professionals in South Africa and they are overburdened. Third, the cultural milieu is vastly different between developed and developing countries, for example in terms of perceptions of the cause of AIDS and the role of the extended family in caring for the sick. Fourth, HIV/AIDS has predominantly affected gay men in developed countries until recently, whereas in South Africa HIV/AIDS has mostly affected heterosexuals overall. Fifth, injection drug use has become a significant means of HIV transmission in developed countries in marked contrast to South Africa where it could be less than 1% of all HIV cases. Finally, ARV treatment is widely available in developed countries but it is still out of reach for most HIV-infected South Africans. Consequently, mortality associated with AIDS has been significantly reduced in countries like the US while AIDS remains the main cause of death in South Africa.

But Freeman concluded that despite the limited applicability of a lot of the research in developed countries, "to ignore existing knowledge would be shortsighted" (p. 145). I agree with this viewpoint and I believe that there are things that we can learn from the broad literature on AIDS-related bereavement, as long as we remember the crucial differences that exist in the social contexts of AIDS.

Prevalence of AIDS-Related Bereavement

Countless numbers of people around the world have experienced or will experience bereavement as a result of AIDS-related deaths. In the US and other developed countries of the world, AIDS-related deaths declined sharply after 1996 when ARV treatment became available (Deeks, Smith, Holodniy, & Kahn, 1997; Rabkin & Ferrando, 1997). As the number of AIDS deaths has declined in the US and other developed countries, there has been a corresponding decline in the number of research studies dealing with AIDS-related bereavement, both of which peaked in the 1990s (Mallinson, 1999a). Bereavement due to AIDS is no longer viewed as the severe psychosocial stressor it once was. Sikkema, Kochman, DiFranceisco, Kelly and Hoffman (2003) explained that "its impact may be diminished because of greater optimism concerning treatment effectiveness, or because persons have gained experience in coping with multiple AIDS losses in the 20 years since the disease first appeared" (p. 167).

South Africa, in contrast, has witnessed a steady increase in AIDS-related deaths in recent years. While there are no known studies measuring the prevalence of bereavement due to AIDS among South Africans, it is reasonable to assume based on anecdotal evidence, published media reports and AIDS mortality statistics that it is endemic in South African society. It has become routine to read news headlines about the scourge of AIDS in South Africa (Whitelaw, 2000), how AIDS has cut life expectancy (Henderson, 2000), that local cemeteries are running out of space (Masland, 2001), and that the funeral industry has experienced exponential growth (McClelland, 2002). Singer (2001) proclaimed that "as AIDS continues to claim the country's young, it has transformed black neighborhoods into open-air funeral parlors and neighbors into widows, orphans, and grieving relatives" (p. 34).

In the 1980s, the growing number of AIDS-related deaths in the gay community in the US was described as resulting in "a secondary epidemic of AIDS-related bereavement" (Martin, 1988, p. 856). For each death, there are friends, family, and other loved ones who grieve that loss. In South Africa, it would not be an exaggeration to declare that a secondary epidemic exists as a result of the accumulation of deaths from AIDS. We have seen in the US how AIDS deaths altered the psyche of the gay community, leaving many bereaved men to go on living in a world in which their entire social network had been decimated (Schwartzberg, 1996). Individual and community-wide traumatization in the US context resulting from multiple AIDS-related loss has been widely discussed in the literature (Martin, 1988; Schwartzberg, 1992; Nord, 1997; Martin, & Dean, 1993a; Rofes, 1998). But the AIDS epidemic in South Africa is on a scale far larger, more complex and overwhelming than that witnessed elsewhere in the world. According to Freeman (2004), in the next decade or so in South Africa, almost everyone will know people who have died of AIDS, and "a very large number of people will be deeply, irrevocably and possibly overwhelmingly affected by the virus" (p. 151). Because of the stigma, those affected by AIDS in South Africa are likely to be silent about their grief, and so it is difficult to predict how loss from AIDS and its resulting trauma will play out in South

African society over the long term. Freeman identified two macro-level concerns for South Africa in the future, as a result of people dying from AIDS. The first concern relates to the increasing numbers of children orphaned by AIDS, their susceptibility to mental health problems and whether they will likely to turn to crime, violence and other anti-social behaviors because of "a combination of poverty, no or very little moral education, poor educational levels and psychological instability..." (Freeman, 2004, p. 153). The other concern relates to the increasing numbers of people who will die of AIDS and the overall psychological impact on society grieving so many deaths. Freeman suggested that "overgrieving" may occur, whereby many people will become debilitated from trying to adjust to multiple deaths (p. 153). The other scenario is that people will develop ways (healthy or unhealthy) to deal with multiple deaths so that they do not become overwhelmed.

Factors Influencing Bereavement Due to AIDS

Bereavement associated with AIDS has the potential to be more problematic than bereavement associated with other kinds of deaths because of several factors. Research has shown that individuals who grieve an AIDS-related death confront a host of issues that may complicate the grieving process, and these issues include the nature of the disease, the HIV status of the bereaved, multiple losses, and inadequate support due to the social stigma associated with AIDS (Dane & Miller, 1992; Nord, 1997; Mallinson, 1999b; Houseman & Pheifer, 1998; Catalan, 1995; Sherr, 1995; Maasen, 1998). These and other issues will be discussed in more detail.

A study by researchers in Australia comparing 28 individuals bereaved by AIDS-related deaths with 30 individuals bereaved by cancer-related deaths revealed that the AIDS bereaved group reported greater number of bereavements, more rejection from others, lower levels of social support, and greater reluctance to disclose the cause of death than the cancer bereaved group (Kelly et al., 1996). It is interesting that while there is a lot of literature about factors that influence bereavement due to AIDS, there are few empirical studies besides the one by Kelly et al. that have actually used a comparison group of individuals bereaved by a non-AIDS death. At best, researchers have simply compared their findings on AIDS-related bereavement with those of studies in the literature on general bereavement (Folkman, Chesney, Collette, Boccellari, & Cooke, 1996). As Kelly et al pointed out, there is a need for more systematic comparisons "to assess differences in the experiences surrounding the death and afterward that are thought to increase the potential for psychological morbidity in an AIDS death (such as stigma, lower levels of social support, multiple losses), and to evaluate potential differences in acute and longer term grief responses and psychological morbidity" (p. 38).

The Nature of AIDS-Related Illness and Death

Death due to AIDS is rarely a quick and peaceful process. The course of the disease is unpredictable and family members and other loved ones are forced to witness the horrifying deterioration of the patient. Additional characteristics of AIDS deaths that present challenges to family members and loved ones include the long period of anticipating the death and the young age of the patient (Martin & Dean, 1993b; Walker et al., 1996, Sherr, 1995). It is hard to imagine a more devastating cluster of opportunistic infections and cancers associated with a disease. An individual with AIDS is susceptible to a host of opportunistic infections that include wasting syndrome, chronic diarrhea, blindness, thrush, dementia and cancers such as lymphoma and Kaposi's sarcoma (Nord, 1997). The emotional toll on family members and other loved ones is enormous as they watch the patient endure and ultimately succumb to this disease (Brown & Powell-Cope, 1993). They must cope with shock, sadness, frustration, helplessness and sadness as they witness the physical and mental decline of their loved one (Worden, 1991; Stajduhar, 1997).

The widespread availability and use of ARV treatment in the US and elsewhere has altered the course of HIV/AIDS and helped transform it from a quick fatal disease to a more chronic disease (Deeks et al, 1997; Porche, 1999; Karon, Fleming, Steketee & De Cock, 2001). Sadly, this is not the case for most South Africans living with HIV/AIDS, due to the limited availability of ARV treatment. As I have watched people die from AIDS-related causes in South Africa, I am reminded of how it was years ago when I was working with AIDS patients in the US before ARV treatment became available. Images of South Africans dying of AIDS are like flashbacks from my past. I described this experience in an article called *The Twilight Zone: AIDS in South Africa* (Demmer, 2003).

Untimely Deaths

Most of those who die of AIDS in South Africa are younger than 40 years of age (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001). It is always harder to accept the death of someone young and this is especially true for parents mourning the death of a child under 40 years of age (Kain, 1996). Besides parents, others who mourn the loss of a loved one to AIDS are also likely to be young, and most young people are not psychologically ready to deal with the death of peers - it is developmentally untimely. There may be heightened awareness of personal mortality and increased death anxiety among friends and contemporaries (Worden, 1991; Nord, 1997). The high AIDS-related mortality rate has also exposed countless children in South Africa to the death of parents, family members and neighbours. We are only beginning to investigate the multidimensional impact of AIDS-related deaths on children.

Being HIV-Infected

A unique aspect of the AIDS epidemic is that many of those who are grieving an AIDS-related death are themselves HIV-infected and this places an extra burden on them as they mourn (Goldblum & Erickson, 1999). Their grief may be intermingled with feelings about their own health and the prospect of dying (Kain, 1996; Kelly et al., 1996). As Sprang and McNeil (1995) noted, "spouses or significant others who lose a loved one to AIDS must face the possibility that they, too, may have been infected with the HIV virus and they fear the pain and suffering they have witnessed in their loved one" (p. 148). However, empirical studies have not produced conclusive evidence that bereaved individuals who are themselves infected will exhibit substantially more distress soon after the death of their partners than bereaved individuals who are not infected (Summers et al., 1995; Martin & Dean, 1993a; Rosengard & Folkman, 1997). In their study of bereaved HIV-infected and uninfected gay men in San Francisco, Folkman et al. (1996) found that both groups of men were extremely depressed during the months following the death of their partners to AIDS. Seven months after the death of the partner, the overall depressive mood of the uninfected men began to diminish but it remained high for the infected men. Neimeyer and Stewart (1998) suggested that more research was needed to investigate death anxiety in populations that are most affected by HIV/AIDS. So far it seems that neither HIV status or bereavement experience will automatically result in increased death anxiety, and Niemeyer and Stewart criticized the assumption that "death anxieties increase in a simple and linear fashion as individuals shift from being at-risk, to seropositive but asymptomatic, to symptomatic with AIDS" (p. 583).

Guilt

It is not uncommon for bereaved individuals in general to experience guilt that they survived while their loved one did not, and to question whether they did enough for their loved one while they were alive (Dane & Miller, 1992; Nord, 1997). This is frequently the case among individuals bereaved due to AIDS. Kain (1996) noted that "survivors, particularly those who are HIV negative, may be steeped in survivor guilt, which prevents them from fully engaging in the bereavement process" (p. 220). In communities devastated by AIDS-related deaths, the bereaved may regularly question why they are still alive while their peers are not (Nord, 1997). The bereaved may also feel guilty for infecting their loved one and being responsible for causing their death (Worden, 1991).

Being a Caregiver

It is well documented that a high level of psychological distress is associated with caregiving in general. Caregivers may experience financial hardship, disruption of family life, depression, fatigue, sleep problems, and feeling hopeless about the future (Schulz, Visintainer & Williamson, 1990). Rosengard and Folkman (1997) studied suicidal ideation and bereavement among caregiving partners of men with AIDS in San Francisco and found that caregiving burdens and lack of social support were associated with high levels of suicidal ideation. Unlike other illnesses, AIDS forces caregivers to be secretive about the reason for the loved one's ill health, so they may receive little assistance with caregiving. The emotional and physical strain of caring for a person dying of AIDS can be overwhelming to say the least, and it can result in "survivor's fatigue" (Kain, 1996, p. 219). Grief may become exacerbated due to unresolved feelings of anger toward those who did not offer to help as well as to the deceased. Caregivers may feel anger and frustration that despite all their efforts, their loved one still died (Kain, 1996).

Stigma and Lack of Support

Probably the biggest factor that distinguishes AIDS-related bereavement from other types of bereavement is the social stigma that is attached to AIDS. Since the first cases were reported, AIDS has been regarded throughout the world as a highly stigmatized disease. Brown, Macintyre and Trujillo (2004) pointed out that "one of the most surprising elements of AIDS stigma is its ubiquitous nature even where the epidemic is widespread and affecting so many people, such as in sub-Saharan Africa" (p. 49). They commented that AIDS stigma is caused by "fear of illness, fear of contagion, and fear of death" (p. 50). Family, friends, and health care workers can be stigmatized by virtue of association with someone who has HIV/AIDS and this is called "secondary stigma" (Brown, Macintyre and Trujillo, 2003, p. 51). AIDS stigma is manifested in several ways including silence, shame, denial, fear, anger and violence.

South Africa can be a hostile place for people who publicly acknowledge their HIV status. Take the example of Gugu Dlamini, a 36-year old female AIDS activist, who was beaten to death at the end of 1998 in the township of KwaMashu by a mob who accused her of degrading her community by revealing her HIV positive status. This barbaric killing prompted concerns that those affected by AIDS would be driven further underground ("Widespread horror over killing", 1999). Five years later, another incident occurred that exposed the extreme nature of AIDS-related stigma in South Africa. In December 2003, Lorna Mlosana, a trainee educator with the Treatment Action Campaign, South Africa's largest AIDS activist group, was gang-raped and when she revealed that she was HIV-infected, she was beaten to death by her furious attackers ("AIDS activist's killing", 2003). The stigma and silence surrounding AIDS in South Africa became the theme of the 13th International AIDS Conference that was held in Durban in July 2000 and the title of the conference was appropriately called *Breaking the Silence*.

Multiple Loss

The professional literature on AIDS-related bereavement has focused substantial attention on the phenomenon of multiple AIDS-related loss, due to the high number of AIDS-related deaths within gay communities in developed countries. Nord (1997) wrote a comprehensive text on this issue titled *Multiple AIDS-Related Loss: A Handbook for*

Understanding and Surviving a Perpetual Fall. But the text is mostly limited to bereaved gay men living in the US context. The scale of AIDS-related loss in South Africa is unprecedented in the world. Considering the high prevalence of AIDS-related deaths in South Africa, it is not uncommon for individuals to lose several members of their family to AIDS, in addition to partners, friends and neighbours. However, we do not know much about this phenomenon within the South African context and research is urgently needed to assess the extent and effects of multiple AIDS-related deaths on individuals and communities in this country.

In the US and several other developed countries, a number of studies have shown that bereaved gay men have experienced high numbers of AIDS-related deaths within their social networks. In an early study of gay men in New York City, it was found that respondents had lost on average 6.7 close people to AIDS (Dean, Hall & Martin, 1988). In 1990, the annual incidence of bereavement in this community sample rose to 30%. Among a cohort of gay men participating in a longitudinal HIV research program in San Diego, California, 60% reported an AIDS loss within the previous 12 months, and 43% of this bereaved cohort reported multiple losses within this period (Summers et al., 1995). In South Africa, it can be safely assumed that far more people overall have experienced multiple AIDS-related loss compared to the relatively small homosexual population in the US.

AIDS has been termed a disease of loss (Nord, 1997). Family members experience various losses throughout the course of the patient's illness, including the loss of the person they once knew as he or she declines (Demmer, 2002a). Other losses include hopes and dreams for the future, feeling of being in control and predictability of life events, physical intimacy, social, financial, and emotional support (Walker et al., 1996). Those who are bereaved in South Africa are subjected to ongoing loss, meaning that they are forced to witness the deaths of a number of people to AIDS within their social network. The phrase "bereavement overload" was coined by Kastenbaum (1977) to describe the experience of elderly people who lose many of their friends in a relatively short period of time, and it has been applied to those grieving multiple AIDS-related deaths as well (Bigelow & Hollinger, 1996; Nord, 1997). In communities devastated by AIDS, there is "a never-ending cycle of perpetual grieving" (Cho and Cassidy, 1994, p.

275). The constant onslaught of AIDS-related deaths does not allow the bereaved individual enough time to grieve a loss before another death occurs, and this complicates the grieving process. Each time a death occurs it reminds the individual of a previous loss, especially when previous losses are unresolved (Nord, 1997; Walker et al., 1996). As a result, bereaved individuals may become "emotionally overwhelmed, physically exhausted, or spiritually demoralized" (Mallinson, 1999, p. 167).

Nord (1996) indicated that individuals who experience multiple AIDS-related loss may protect themselves by deadening the pain or going into denial (psychic numbing). There may be changes in personality and the following emotions may dominate: pessimism, rage, disillusionment, despair, and powerlessness. Furthermore, multiple AIDS-related loss may result in self-destructive behaviors such as alcohol and drug use, suicide and engaging in high-risk sex behaviors to purposely become infected with HIV (Villa & Demmer, 2005). Multiple bereavement episodes may lead to the development of post-traumatic stress disorder or major depressive disorder (Martin, 1988). To address the plight of those grieving multiple AIDS-related deaths, Biller and Rice (1990) stressed that "participants need to tell their stories over and over again" (p. 287). However, this is not always feasible in reality. In the larger community, those bereaved by AIDS are often forced to be silent. They may feel isolated because the larger community does not want to know their feelings. Furthermore, denying one's grief may lead to shame and guilt over the loss, the relationship, and oneself.

Conclusion

The HIV/AIDS crisis in South Africa has been described as "a medical holocaust" because of "inadequate health care, poor education and social stigma" ("Pseudoscience in South Africa", 2000, p. A28). The high number of AIDS-related deaths in South Africa has created a parallel epidemic of mourners who grieve the loss of loved ones to AIDS. Although AIDS-related bereavement has received substantial attention in the West, we know very little about the bereavement experiences of people in South Africa, a country which has been impacted by AIDS-related losses on a scale never witnessed before in the history of the HIV/AIDS epidemic. Most research on AIDS-related bereavement has been conducted on white, middle class gay men in the West, and there are obvious limitations in applying knowledge from this context to a vastly different one in South Africa. However, this research can heighten our awareness of issues that could affect mourners in the local context. Now that the background literature has been reviewed, we turn our attention to the next section which deals with the methodology of the study. Chapter Five describes the research methodology and Chapter Six presents profiles of the participants in the study.

PART THREE: METHODOLOGY

CHAPTER 5

Methodology

This chapter describes the research methodology used in the study and my rationale for the selection of the qualitative paradigm. This is followed by a discussion of the sampling process, data collection and analysis procedures, ethical concerns, as well as challenges presented by this type of study.

Research Design

As noted, a number of studies have explored AIDS-related bereavement in the US and elsewhere in the West, but there is a paucity of research about this phenomenon pertaining to the South African context. Despite the high mortality rate associated with HIV/AIDS in South Africa, there is no documentation in the literature to my knowledge that explores the impact of AIDS-related deaths on individuals in this country. At the same time, I knew that efforts were being made by various NGOs around South Africa to address the needs of individuals bereaved by AIDS, especially children. And certainly, there was evidence of other types of bereavement interventions being developed and evaluated (Strydom & Fourie, 1998). For this reason, as well as the fact that I had lost a parent to AIDS in South Africa, I decided it was important to research the phenomenon of AIDS-related bereavement as well as to gather information from a small group of key informants about this phenomenon and what was being done to address it. I felt very comfortable with the selection of my research topic and was confident that my passion for this topic would sustain me throughout the duration of the research process. As Strauss and Corbin (1998) asserted, "it is important to remember that whatever problem is selected, the researcher will have to live with it for quite a while, so the final choice should be something that engages his or her interest" (p. 37).

I decided to employ qualitative methods for this study. Henwood and Pidgeon (1995) suggested using qualitative methodology when exploring a new area of enquiry and when "there is a need to be sensitive to people's own understandings as seen from their local frames of reference" (p. 116). Strauss and Corbin asserted that there are usually two major reasons for choosing qualitative methods. One reason is the preference of the researcher and the other reason is the nature of the research problem. Strauss and Corbin suggested that the researcher may prefer this type of research because of his/her temperament or orientation as well as his/her prior experiences with research. As this was my first exposure to qualitative methods, I did not come into the research situation with a previous bias or preference for qualitative methods. I decided on this method because after examining both quantitative and qualitative studies of AIDS-related bereavement in the US, it seemed that a qualitative study would provide a better understanding of the lived experiences of people who have lost loved ones to AIDS in South Africa. Also, because no research currently exists in the South African context about this phenomenon, I believed that an exploratory study would be most appropriate.

Padgett (1998) described qualitative research as a journey of discovery. The opportunity of listening and observing participants in their environment can produce amazing insights. As I began to collect data, I realized my hunch to use qualitative methodology was right, and I was particularly gratified by the ability of this paradigm to obtain rich, meaningful data from participants. I realized that I would never have been able to obtain the same quality of information with quantitative methods which I have used predominantly in past research endeavours. I found that I really enjoyed this methodology because it enabled me to understand better the unique perspectives and life worlds of participants. I also found the interview process to be rewarding as I felt that it connected me in a more human way with participants than quantitative methods ever did.

My choice to use qualitative methods, however, was primarily determined by the nature of the research problem I wished to investigate. The purpose of my study was to provide an in-depth account of the experiences of individuals bereaved due to AIDS in South Africa, and I felt that qualitative methods would facilitate a process of introspection and enable participants to tell their stories in their own words. The choice of qualitative methods reflected my interest in gathering data from the participants' perspective, and my belief that this type of design would elicit deeper and richer information about the bereavement experiences of individuals than quantitative research methods could. Strauss and Corbin (1998) indicated that qualitative methods involve "going out into the field and finding out what people are doing and thinking...to understand the nature and meaning of experiences of people with problems" (p. 11).

Their opinion was that qualitative methods were best suited for researchers who wished to gain details and insights relating to feelings and thought processes "that are difficult to extract or learn about through more conventional research methods" (p. 11).

There has been a rise in the popularity of various methodologies known as "qualitative research", especially in the past 10 years (Denzin & Lincoln, 2000; Rennie, Watson, & Monteiro, 2002). Carverhill (2002) highlighted the close fit between qualitative research and applied work with the dying and the bereaved:

> Perhaps part of the appeal of doing qualitative research lies in its pluralistic promise for exploring multiple ways of knowing – multiple truths. In this sense it seems very akin to the contemporary teachings of our own field which emphasizes the range of individual differences in styles of grieving and processes of mourning. (p. 198)

I felt that a first-hand description of the every-day concerns and experiences of people bereaved by AIDS could guide the efforts of social workers who are interested in helping this vulnerable population. The dearth of discussion or research in the mental health literature about the concerns and needs of individuals bereaved due to AIDS in the South African context was a major factor influencing my decision to undertake this study and to use qualitative methods. Furthermore, my goal in using this paradigm was to give a voice to those who are bereaved due to AIDS. I wished to bear witness to their personal struggles. Waldrop (2004) indicated that "the opportunity to discuss a difficult experience with an interested and nonjudgmental researcher can generate positive feelings and hope for change among those who feel disenfranchised" (p. 242).

Grounded theory provided the methodological framework for data collection and analysis. Grounded theory is a general methodology for developing theory that is based on systematic qualitative data collection and analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1998). As Trainor and Ezer (2000) asserted, the goal of grounded theory "is to produce abstract concepts and to develop propositions about the relationships between these concepts" (p. 648). It is particularly amenable to researching topics that have received little attention (Burns & Grove, 1987 in Stajduhar, 1997). Carverhill (2002) pointed out that it is not a well known fact but death and dying was the subject of the early grounded theory research of the pioneers of this type of enquiry, Barney Glaser and Anselm Strauss.

Before proceeding further, let me make a comment about the role of the literature review in qualitative research. According to Shank (2002), one school of thought is that "ignorance is bliss", meaning that it is best to review the literature at the end of data collection so that one has a fresh perspective when collecting data. The other school of thought recognizes the importance of understanding the literature on the topic prior to collecting data. Because I was quite familiar with the literature on AIDS-related bereavement long before I decided to pursue the present research study, I did not have the option of forgetting all that I had read on this subject. But as Shank indicated, reviewing the literature beforehand can demonstrate that our knowledge of a topic is "somehow incomplete" and that "we simply do not understand it well enough" (p. 124). In my case, I realized from my review of the literature that very little was known about AIDS-related bereavement in the South African context, so it was useful in this regard.

Sample

Two non-probability samples were used. The primary sample, consisting of individuals who had lost loved ones to AIDS, was recruited from a variety of sources in and around Durban, KwaZulu-Natal. They included hospitals, non-governmental organizations (NGOs), support groups, and referrals through professionals, friends and family. Following Horowitz, Ladden, and Moriarty's (2002) suggestion, I attempted to identify "gatekeepers" who could help locate potential participants in the community. I usually contacted key persons in various community organizations (e.g. Chief Social Worker, Program Director), described the nature of the study to them and requested their assistance in recruiting participants for this study. If they managed to locate anyone who was interested in participating in the study, they gave the individual my phone number to contact me directly. When prospective participants contacted me, I described the study to them and what their involvement would entail, and I invited them to participate in the study. An interview was then scheduled at a mutually agreeable time and location. On a few occasions, participants forgot the appointment or got lost, and this delayed the data gathering process a bit. When things did not always go exactly as planned, this naturally created some anxiety for me, since I had scheduled a block of time to be in South Africa to collect data and I was concerned that I would not be able to get all my interviews done on time. Thankfully, everything worked out well in the end.

I wish to add a comment about recruiting participants through these gatekeepers. Gaining access to people to talk about sensitive issues around HIV/AIDS is not easy and gatekeepers can be a useful means of recruiting participants. However, the drawback to using gatekeepers in community organizations and other NGOs is that the findings are likely to be skewed toward individuals who are being served by these organizations (Pierret, 2000). The experiences of bereaved individuals who are not connected to services are ignored. This is an important limitation to bear in mind when interpreting the findings of the present study since many participants (though not all) in the sample were receiving some kind of service from a community organization.

Theoretical and purposeful sampling was used in the selection of the bereaved participants. Participants had to be over the age of 18 and report an important relationship to a person/s that had died of AIDS at some point in the recent past. Participants were given the opportunity to determine who was important in their lives rather than me giving them predetermined categories of relationships. It was not presumed that the relationship to a blood relative was more important than that of a close friend, or partner. The sample was also not limited to participants who had lost a loved one to AIDS within a set time period (e.g., no more than two years after the death). I felt that opening up the sample to participants who experienced AIDS-related deaths from some time ago (e.g., five years ago) as well as participants who had lost loved ones recently, would provide a picture of the nature of bereavement for individuals at different points during the AIDS epidemic in South Africa (chronosystem).

My main selection criterion was that participants had to be adults who had experienced the loss of a loved one to AIDS. Because of the stigma and secrecy surrounding HIV/AIDS in South Africa, I was concerned about my ability to recruit participants who would be willing to share their experience. I decided to focus my research on residents in and around Durban, KwaZulu-Natal because I needed access to participants who were nearby. This was important because my interviews would be in depth and I needed to follow up with participants. I also had to consider the emotionally draining nature of the data collection process and the possible psychological reactions of participants. I felt that these factors took precedence over recruiting large numbers of participants from all over South Africa which I would have done if I was conducting a quantitative study and if I wanted to ensure that my findings would be generalizable. Rather, my purpose was to gather and analyze qualitative data from a group of bereaved participants in one context and I had no intention of purporting that this information would be representative of all people bereaved by AIDS in South Africa. Shank (2002, p. 94) asserted that it is better in qualitative research to have samples that are "fertile" than "typical" ones. He indicated that "generalizability is most often a push toward breadth, and qualitative research is much more concerned with depth" (p. 94).

My sample eventually consisted primarily of Black women who were poor and living in and around the Durban area. Many participants were HIV-infected themselves. Although it was not a conscious decision on my part, the sample ended up resembling the pattern of those who are predominantly affected by HIV/AIDS in South Africa (Johnson & Budlender, 2002).

The number of participants was determined as the research progressed. I recruited and interviewed participants until it was determined that no new themes emerged from the analyses, categories were developed in terms of properties and dimensions, and relationships among categories were well established and validated (i.e., a state of theoretical saturation was reached) (Strauss & Corbin, 1998). A total of 18 participants from the primary sample were interviewed for this study. Qualitative studies typically consist of small samples since the aim is to interview participants in depth. Based on the amount and quality of data generated, I felt that the size of the sample in this study was sufficient to provide for contextually rich narratives that would deepen our understanding of the grief response and coping strategies of people bereaved by AIDS in and around Durban, KwaZulu-Natal.

Purposive sampling was used in the recruitment of key informants. This secondary sample consisted of eight human service professionals (including social workers, a psychologist and a nurse) who were directly involved in providing services to people from all areas of KwaZulu-Natal who were infected and affected by HIV/AIDS. They worked in various settings including a hospital-based HIV/AIDS support program, a large child welfare NGO whose mission included providing services to children infected and affected by HIV/AIDS, two church-based NGO's serving people with HIV/AIDS in outlying rural areas, an in-patient palliative care program for AIDS patients, and a NGO that specialized in providing support groups and counseling for people affected by HIV/AIDS.

Data Collection

Data collection with the primary sample of bereaved individuals took place between May and July 2004. Data were collected from key informants during June and July 2004. The purpose of the interviews with participants in the primary sample was to gather as complete a picture as possible of his/her subjective experience – and overall to gain insight into and make discoveries about the means by which a sample of individuals in South Africa grieved the loss of loved ones to AIDS. The expectation was that this information would allow for the development of subsequent explanatory or predictive research studies on AIDS-related bereavement in South Africa.

Interviews with Participants Bereaved by AIDS

Data were collected for this study by conducting in-depth interviews with participants. All interviews were conducted by me. The interviews were scheduled at a time and place convenient for the participants. All interviews were conducted face-to-face in a private office at an organization or on a few occasions at the participant's home at their request. Most interviews took place in settings with only the participant and researcher present. However, some participants did not speak English, and I made a choice during the study not to automatically exclude them, as I wanted to give them a voice too. These participants were usually very poor and living under extreme hardship and I felt that it was necessary to include their stories and perspectives. In these instances, I used a translator who also was the participant's counselor at the setting where they received services. The advantage of this was that the translator was not another stranger in the interview situation, but rather someone with whom the participant was already close and who they trusted. Granted, using a translator can be somewhat awkward and considerably slows the pace of the interview, but I felt that the positives outweighed the negatives. Overall, though, most participants recruited for this study did speak English, so I did not encounter this situation often (I used a translator for only three participants).

Semi-structured interviews were used to understand the breadth of participants' experiences. The advantage of the interview as a research tool is that it is possible for the researcher to listen to respondents and to investigate their thinking firsthand. I developed an interview outline based on an extensive review of the literature on AIDS-related bereavement, literature pertaining to the context of AIDS in South Africa, as well as on my own experiences and hunches. Using less structured forms of questioning enables researchers to obtain information that cannot be expected using a more structured format (McAuliffe & MacLachlan, 1992).

Key components in conducting successful in-depth interviews are to establish rapport with participants, create a non-judgmental atmosphere and convey interest in and respect for the experiences and knowledge of participants (Fontana & Frey, 1994). Each interview began with me thanking participants for volunteering for the study and I provided a brief statement about my experiences with AIDS-related bereavement both professionally and personally, having lost my father to AIDS. I reiterated the purpose of the study and expressed my desire to learn more about their experiences with AIDS and bereavement within the South African context. Participants appeared to respond well to this introduction and sensed my sincerity in wanting to understand their experiences. I believed that briefly sharing some of my personal experiences with AIDS-related loss was important, especially for those participants who might have been reluctant to share their experiences with someone who appeared to be different to themselves.

Next, I gathered basic demographic information about each participant, including gender, ethnicity, age, sexual orientation, occupational status, household composition, and religion. Information was obtained about the deceased person/s including name, gender, ethnicity, age at death, when he/she died, and relationship to the participant. After this, participants were asked several guiding questions such as: "Please tell me, in our own words, your experience of losing (name of loved one/s) to AIDS" and "What stands out for you, good and bad, when you think back about your loss?" The objective was to keep the interview as open-ended as possible, to enable participants to create their own story and to lead the interviewer to wherever their thoughts took them.

A non-directional approach, active listening techniques, and open-ended questions were employed that encouraged participants to tell their stories from their own frame of reference (Kvale, 1996). Throughout the interview, probing and clarification questions were asked to further explore their experiences (Guba & Lincoln, 1989). The grand tour questions led to a funneling or narrowing to more specific questions. I used things that a participant said to generate further questions in subsequent interviews – what Franklin (1997) refers to as "cross-connections" (p. 104). The collection and analysis of data proceeded at the same time, allowing me to change focus or pursue leads or gaps revealed by the ongoing analysis. The first few interviews were like pilot interviews that informed subsequent interviews.

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My experience as a researcher and clinician helped considerably in conducting the interviews. As an experienced researcher, my curiosity and questioning yielded rich information from participants. And my training as a grief counselor allowed me to be sensitive to the psychological processes of participants as they explored feelings which often were painful and upsetting. Oskowitz and Meulenberg-Buskens (1997) offered the following advice to researchers preparing to conduct a qualitative investigation of a sensitive issue:

> For respondents to be heard, researchers have to be receptive to hearing what respondents have to say. To enable respondents to speak and their voices to be heard, it is our contention that researchers need to have empathy and compassion and should strive towards the establishment of a relationship of mutual trust with respondents. These qualities are not only humanitarian prerequisites, they are also crucial in the process of gaining valid data. For it is only in a relationship of mutual trust that respondents will risk voicing their feelings. (p. 87)

Each participant was interviewed for approximately one hour with a follow-up interview of the same duration a week or two later. I decided, due to the subject matter and the potential emotional strain on participants (as well as me), to limit the duration of each interview to about one hour and to allow a "breathing space" between interviews. I maintained contact with participants between interviews to check on how they were doing and to remind them of the next meeting. I did this primarily through phone calls and if I could not reach them, I contacted a key person at the organization where they were interviewed to enquire about them. I believe that most participants sensed my concern for their well-being and all of them showed up for the follow-up interviews.

Content of Interviews

Participants were encouraged to share their story of bereavement from AIDS. The following areas were addressed in my interviews that were guided by social ecological theory:

- Biographical data.
- Impact of AIDS and associated losses on the individual and family (microsystem).
- Relationship between the bereaved individual and his/her family with the community (mesosystem).
- The bereaved individual's experience and interaction with the health and social welfare system (exosystem).
- Perceptions about national policy, funding and government values regarding AIDS and those affected by AIDS, and cultural influences on AIDS-related bereavement (macrosystem).
- The effect of political, cultural and social changes as well as medical advances on the bereavement experience (chronosystem).

Pierret (2000) raised an interesting point for researchers studying participants affected by HIV/AIDS; that we need to bear in mind the different stances adopted by participants because it will determine what the participants say and the type of data collected. The interview is an opportunity for talking and each participant may understand this opportunity differently. As Pierret suggested, it may be an opportunity to tell a life story or for bearing witness, it may be a time for breaking the silence and sharing one's secret, or it may be perceived as a time for seeking help or counseling. This point also applies to the key informants that I interviewed.

Interviews with Key Informants

In-depth focused interviews were also conducted with eight key informants. These interviews which were also tape-recorded were obviously of a different nature from those conducted with bereaved participants. They were of a less personal nature and focused more on informants' experiences and attitudes about caring for people affected by HIV/AIDS. They averaged an hour and a half long and were conducted at the office of each key informant. In every instance, I found key informants to be enthusiastic about my research and they were very receptive to being interviewed about their experiences (personal and professional), opinions relating to AIDS-related bereavement, and how they were addressing this issue. Specific topics that were covered in the interview included:

- Some biographical data.
- Description of the organization (services offered, clientele, staffing).
- Experiences and thoughts about bereavement due to AIDS.
- Services that were being offered to help people cope with deaths due to AIDS.
- Needs, challenges, ideas and goals with respect to providing services to people infected/affected with HIV.
- Opinions about the government's handling of the AIDS crisis and functioning with limited resources.
- Attitudes about the roll out of ARV treatment.
- Burnout.

Recording of Data

As Strauss and Corbin (1998, p. 32) attested, research rarely goes along as planned and can sometimes be a "messy affair". With the participants' permission (from both samples), I audiotaped all interviews. During the first two weeks of data collection, two tape recorders were troublesome and I had to deal with poor quality sound at times. But I was successful with the third tape recorder. I learned to come to each interview prepared with an ample supply of cassettes, batteries, a back-up tape recorder, consent forms, note pads, pens, and a date book. After a while, I felt that I was suitably in control and could handle most obstacles that arose during the research process. This is, of course, not to say that I did not have moments when I was overcome by frustration, impatience, and anxiety but I was better able to handle matters as time progressed.

I transcribed the tapes myself. I double-checked the transcripts line by line for accuracy as I listened to the tapes. I made sure that any identifying information was removed from the transcripts. Handwritten notes or analytic memos supplemented the audiotaped information. The primary purpose of these notes was to record my emotional response to the interviews (including my thoughts, feelings, biases, and hunches) and to help me analyze material as it evolved. Ely, Anzul, Friedman, Garner and Steinmetz (1991) called analytic memos "conversations with oneself about what has occurred in the research process, what has been learned, the insights this provides, and the leads these suggest for future action" (p. 80). She suggested that the researcher see emotions as a source of strength and "mining one's emotions for their intellectual lessons" (p. 136). Similarly, Strauss and Corbin (1998) advised researchers to "question everything" (p. 96). I found that these notes provided a useful way for me to express some intense emotions that arose from the interviews. They fulfilled both a supportive and a technical function and I believe they enhanced the rigour of my research. Rowling (1999) reported that field notes and journal entries act as a monitoring system and enable the researcher to identify preconceptions and assumptions.

Analysis of Data

All audiotapes and notes were locked in a secure location both when I was in South Africa as well as in the US. I prepared transcripts from the audiotapes and notes taken after each interview (with both samples). Data were analyzed using principles of grounded theory (Glaser & Strauss, 1967). The transcripts were carefully read and the emergence of patterns and themes were noted. Transcripts and field notes were systematically analyzed using conceptual coding and the constant comparative method (Strauss & Corbin, 1998). Data collection, coding and analysis were done at the same time, in alternating sequences. Strauss and Corbin (1998) emphasized that "analysis begins with the first interview and observation, which leads to the next interview or observation, followed by more analysis, more interviews or fieldwork, and so on. It is the analysis that drives the data collection" (p. 42). Furthermore, they asserted that alternating data collection with analysis "enables validation of concepts and hypotheses as these are being developed" (p. 46).

I achieved familiarity with the data by constantly listening to the audiotapes, reading the transcripts, reading the field notes, and listening to the audiotapes and reading the transcripts simultaneously. In the transcripts and field notes, code names were assigned to statements that highlighted particular aspects of the bereavement experience of participants. A word or phrase that captured the meaning within a section of the text was written in the margin of the transcript. Following the coding procedures outlined by Strauss and Corbin (1998), phenomena were grouped into categories of like meaning and the contents of the categories were compared between and within interviews. Thus, there was a continuous process of collecting data and comparing data with previously coded data. As recommended by Strauss and Corbin, I compared incident to incident, looking for similarities and differences among their properties. I also compared categories according to their properties and dimensions. Strauss and Corbin (1998, pp. 94-95) suggested two comparative techniques which I used whenever I could. The first one is the "flip-flop" technique, which means turning the concept upside down and looking at it from the opposite side to bring out significant properties. The second comparative technique is making systematic comparisons, which involves comparing an incident or event in the data to one documented in the literature or even recalled from one's personal experience.

At times, as suggested by Strauss and Corbin, I described to participants what I thought I was finding and asked them whether my interpretation matched their experiences and opinions. I was always cognizant of the fact that it was not my perception or perspective that mattered, but rather how participants interpreted things. What was important was not only what they said but how they said it. At the same time, I learned to become more secure about my discoveries. As someone whose research experience has been mainly with quantitative methods, I had to change my way of thinking and I had to learn to listen to the data and adopt a less controlling attitude toward my research. Another concept that I had to learn was the importance of classifying events, acts, experiences etc, and not focusing on the specifics of a case or individual but rather on the data themselves. As Pierret (2000) indicated:

> The aim should be to reconstitute major categories of analysis and to bring to light the beliefs that, running through interviewees' accounts, enable us to compare them. But we must bear in mind that the results do not correspond to persons but to structures in what individuals have to say in an interview setting as part of a research project. (p. 1592)

The interviews continued until no new categories emerged. After participants from the primary sample had completed their interviews, I summarized the background information provided by each participant. In order to assess the trustworthiness (Lincoln & Guba, 1985) of the coded categories, I enlisted the help of two colleagues with experience in qualitative methodology who reviewed the transcripts and the coding.

Ethical Considerations

In light of the sensitive nature of the research topic as well as the mode of investigation, careful consideration was given to ethical concerns and addressing the needs and rights of participants (from both samples). I did my best to follow the guidelines offered by Shank (2002) for being an "ethical" qualitative researcher, which are as follows:

- Do no harm (e.g., obtain informed consent, ensure that participants are not harmed in any way, and be sensitive to the possibility that one's questions could evoke painful feelings).
- Be open (e.g., do not observe people without their knowledge, be willing to accept participants' viewpoints and decisions, allow them to read any material collected on them).
- Be honest (e.g., do not lie to participants, do not delude oneself, admit when one is wrong).

- Be careful (e.g., make sure that all work is documented, create an audit trail, only make claims and conclusions that can be traced back to the data collected).

This study was approved for protection of human subjects by the Ethics Committee at the University of KwaZulu-Natal as well as by Lehman College (where I am employed). It is the policy of my university that all research conducted by faculty must be approved beforehand by the university's own ethics committee or internal institutional review board (IRB).

Before the study began, all prospective participants were informed about the purpose of the study and given assurance about confidentiality and that their participation was voluntary and that they could withdraw at any time. They were reassured that their willingness or refusal to participate would in no way affect the services they or their loved ones received at any NGO, hospital etc. Informed, written consent (see Appendix I) was obtained prior to the first interview. Participants were advised that their verbal consent was ongoing; this is an important part of qualitative research because data and the dynamics around the collection of data change frequently. Munhall (1988) argued that it is essential for researchers to allow for negotiation and renegotiation of consent on an ongoing basis as informed consent on its own is just a "static, past tense concept" (p. 161).

Participants were informed that the interviews would be tape-recorded and I explained that my reason for doing so was that this was a more effective way to gather information than just taking notes. I experienced no resistance to tape-recording the interviews. I also explained that I would be doing all the transcripts myself. Participants were informed that transcripts and any handwritten notes would be labeled with an ID number and a pseudonym would be used to ensure anonymity. Participants were again assured that all information would be kept confidential and locked in a safe place.

As Horowitz, Ladden, and Moriarty (2002) indicated in their research with vulnerable families, "the research process may be stressful for participants when it elicits sensitive discussions, traumatic memories, or distressing feelings" (p. 328). Thus, participants were informed of potential risks as well as benefits associated with participation in the present study. They were advised about the possibility that the interview could raise some uncomfortable feelings (e.g., sadness, heightened grief). Waldrop (2004) indicated that preparing for a qualitative study requires "thoughtful consideration of potential participant reactions" (p. 243). I made sure that participants were debriefed at the end of each interview and at the conclusion of the interview process. They were given my phone number to call if they needed to, and they were given a list of local community resources they could contact for support and assistance.

It should be pointed out that my concern for the emotional well-being of participants overrode my curiosity as a researcher. I attempted to balance my role as curious observer on the one hand with empathic human being on the other. I used a variety of empathic verbal and non-verbal responses to facilitate communication and to put participants at ease. I did not push participants and gave them permission throughout the interview process to take time out whenever they felt they needed it. If my intuition told me to slow the pace or change course or to suspend the interview, I did so. I was cognizant of the emotional impact on participants of sharing information that for many had been repressed or too emotionally charged to deal with in the past. My twenty years of clinical experience was of considerable benefit in enabling me to create a safe holding environment for participants' painful and uncomfortable feelings. I adjusted my stance as participants moved through different areas of their experience. I have mixed feelings about Waldrop's assertion that this type of interview not be construed as a form of "mental health assistance". She indicated that the researcher's response to a participant's reaction is important, but she recommended that instead of offering comforting words when a participant is crying, to "just sit quietly and wait" (p. 243). I was aware that my purpose was not to provide "therapy" to participants and I believed in the importance of waiting and listening, but I also felt a responsibility to react like any human being would react when someone was in a great deal of emotional pain. There were times when I stopped the interview and suggested that we talk about what just happened, to acknowledge the participant's feelings and to assess whether to proceed. Several times, certain issues came up that I felt were important enough for the social worker who was working with the participant to be made aware of. Of course, this was always with the participant's consent and I never breached confidentiality. There were times when I gently encouraged participants to talk with a counselor or social worker about this issue if they had not already done so. It would be correct to say that I did not view myself as a detached observer (neither did I want to). Rowling (1999) supported this perspective and asserted that being detached (which is commonly advised in textbooks on conducting research) prevents the researcher from fully eliciting and understanding the emotional reactions of participants.

Several researchers have discussed the "tension" that exists between being a researcher and a therapist (Nadeau, 1998; Rosenblatt, 1995) or "reporting from double lenses" (Ely, 1991, p. 137). The question is how much distance should one maintain from participants to keep the researcher role and how should one care for participants as someone who is a trained mental health professional? (Peshkin, 1988). I liked Rosenblatt's perspective that in-depth interviews about sensitive issues are "therapeutic experiences: they are "transformative or growth-producing moments, but [not]...focused on growth or healing" (p. 151). I also identified with Rowling's (1999) suggestion that it would help if qualitative researchers in the bereavement field viewed their role as being 'alongside' and 'with' the participant, rather than 'in' or 'out' of the relationship. Otherwise, it becomes a difficult balancing act of not being too 'in' the research process (by being enmeshed in participants' experiences), and not being too 'out' of the research (by being detached) (p. 179). After all, there is increasing consensus in bereavement research that we view participants not as objects but rather active contributors to research on their own loss and grief experiences (Klass, Silverman, & Nickman, 1996).

Many participants acknowledged the need for a study of this kind and expressed the hope that their participation would help others. Participants were informed that they had the right to receive a written summary of the findings once the study was completed, and they were given information on how to obtain this summary. Participants received a payment of R100,00 at the conclusion of each interview, as a gesture of appreciation for their participation in this study. Horowitz, Ladden, and Moriarty (2002) indicated that one way to recruit and retain hard to reach vulnerable individuals is to provide appropriate reimbursement. They indicated that "time and effort, as well as discomfort or difficulty involved in participating, are factors to consider when planning the value for reimbursement or incentives" (p. 325). Given that each interview was about one hour in length, many participants had to travel a far way to come and be interviewed, and that the interviews were emotionally draining, I felt that R100 was suitable reimbursement.

Challenges Presented by the Study

This section documents the main challenges posed by this study and my efforts to address them.

Researcher Bias

According to Strauss and Corbin (1998, pp. 43-46), "the researcher is an instrument of analysis in qualitative studies", and it is important to strike a balance between being objective and sensitive when doing analysis. They assert that while a "state of complete objectivity is impossible", there are some things a researcher can do to minimize subjectivity during analysis. I followed their guidelines whenever possible to obtain objectivity. First, I thought "comparatively" - meaning I compared one piece of data to another and I used examples in the literature and my experience to stimulate my thinking about properties and dimensions in the actual data. Second, I obtained various meanings or interpretations of events and experiences through theoretical sampling. Furthermore, I consulted with several key informants who worked with people affected by HIV/AIDS to check whether my interpretations matched theirs and they also helped me consider alternative explanations. I also became acquainted with a small group of social workers after being invited to a meeting of the HIV subcommittee of the Hospital Social Workers Forum held at the offices of HIVAN (HIV/AIDS Network) in Durban on June 11, 2004 and I bounced ideas and preliminary findings off them. Another method I used to obtain objectivity was to occasionally step away from the data and to consider whether what I thought I was seeing actually fit the data. Finally, I was diligent about alternating data collection with analysis to validate concepts and hypotheses as they were being developed and I checked my interpretations against those of participants at follow-up interviews or across interviews with other participants.

Strauss and Corbin (1998) cautioned that researchers need to be aware when either their own or participants' biases intrude into the analysis. Before I began interviewing participants, I gave careful thought about researching a problem with which I was personally familiar. Could my own personal experience with an AIDS-related death cloud my interpretations? I anticipated that my bereavement experience would deviate from those of my participants in three important ways which would enable me not to over-identify with their stories. First, my loss was ten years ago, so I had plenty of time to adjust. On the other hand, I suspected that the losses of my participants would be more recent and their pain was likely to be more intense than mine. Second, I expected that the lives of participants would be more completely impacted by losses from AIDS than mine had. Whereas I had suffered only one loss to AIDS, my participants were likely to have suffered more. Finally, my experience as a bereaved individual was likely to be very different from those of bereaved individuals in South Africa in terms of socioeconomic circumstances. Nevertheless, I followed the advice of Waldrop (2004) as best I could to keep my emotional reactions in check because I wished to protect participants from dealing with the undue burden of my reactions, and to preserve the integrity and validity of the data.

Because I have had a number of years clinical experience in the US assisting people who are bereaved due to AIDS and have published a number of articles on AIDS-related issues (e.g., Demmer, 2000; Demmer, 2001a), I had to make a conscious effort to see things fresh and new and not to be stifled by this background knowledge and experience. I had to learn to be open and receptive to what I was trying to understand (Ely et al., 1991). This proved not to be as big an obstacle as I anticipated. During the data collection process, I quickly became aware of the unique life circumstances of AIDS bereaved individuals in the South African context compared to those in the U.S. context. It was important for me to acknowledge that I did not know very much about what it was like to have AIDS or to be affected by AIDS in South Africa, despite my own personal loss. I learned that many aspects of my bereavement experience did not mirror those of my participants.

Respondent Bias

Bodgan and Bilken (1992) cautioned that an interviewer's ethnicity, gender, age, and other characteristics could influence the rapport that is established with participants as well as participants' willingness to open up in interviews. Being a White male, I was aware of the possibility that participants might not feel as comfortable sharing their experiences with me. To compensate for potential respondent biases that could arise at the beginning of the interview situation, I opened each interview by making a brief statement about my own background (personal and professional). Originally from Durban where my family still resides, I have spent a number of years living and working in the US. In addition to sharing my extensive professional experience working with people with AIDS and their loved ones, I hoped that disclosing the loss of my father to AIDS would enhance my trustworthiness with participants. According to Ely et al. (1991), when the interviewer shares personal information about himself or herself it "lets the interviewee know that 'you have been there' and can sympathize" (p. 41). I was confident that my personal and professional experience with AIDS-related bereavement would enable me to create a safe and trusting environment for participants to share sensitive information with a complete stranger. I was also aware of the potential for participants to tell me what they thought I wanted to hear or to present themselves or information in a certain way because they did not know whether they could trust me to be themselves. Again, my extensive clinical experience was very helpful. I was able to discern discrepancies between responses (verbal and non-verbal) and I made sure to document my observations and comments in my analytic log.

Sample Size

With quantitative methods, much more emphasis is placed on sampling procedures, size of the sample, and generalizability of results. The present study makes no claim to be representative of all individuals in South Africa (or KwaZulu-Natal for that matter) who are bereaved due to AIDS. But as mentioned before, participants ended up resembling the pattern of those who are largely affected by AIDS in the South African context, based on the most current epidemiological data. With qualitative research, theoretical sampling is used and Strauss and Corbin (1998) made the point that theoretical sampling is not planned before starting the study but rather it evolves during the course of the study. They also make the distinction that qualitative researchers sample "events and incidents and not persons or organizations per se...*and* persons, sites, and documents simply provide the means to obtain these data" (p. 215). In terms of applying the findings to others, Guba and Lincoln (1989) explained that the context is important in qualitative research and conclusions and recommendations are limited to those in similar contexts.

Integrity of the Study

Unlike quantitative methods, the notions of reliability and validity are not accorded the same prominence in qualitative research. Rather, the focus is on the integrity of the study. According to Lincoln and Guba (1985), the following strategies ensure the integrity of qualitative research (i.e., that the findings represent as close as possible the experience of participants): prolonged engagement, member-checking, and peer-debriefing. Prolonged engagement involves spending enough time with participants to build trust with them so that they open up, and staying in the field long enough to fully understand the phenomenon under study and to minimize researcher bias (Lincoln & Guba, 1985). This was achieved by conducting two in-depth interviews (each about one hour long) over a two week period with each participant. The second strategy is member-checking. As themes were identified, I shared them with participants during the follow-up interview so that I could further understand and clarify these categories. Whenever it was possible, participants were given the opportunity to confirm that I had intrinsically characterized their experience (Ely et al., 1991; Lincoln & Guba, 1985). Finally, peer-debriefing involves sharing findings with colleagues, to avoid over-identifying with participants, to check interpretations of data, and to discover information that might be missed (Ely et al., 1991). I met with several social workers in Durban who had experience working with people affected by HIV/AIDS to discuss emerging themes as well as to bounce off some of my hunches, concerns and questions. I also conducted interviews with key informants. All of these individuals provided welcome moral support and validation of many of my hunches and observations.

In my effort to conduct an empirically sound qualitative study, I closely followed the guidelines of Strauss and Corbin (1998) in collecting, recording and analyzing data. I was guided by the following checklist:

- What concepts are being generated from the study?
- Are linkages made between concepts?
- Are the categories well developed?

- Are the concepts examined under various conditions and are they explained?
- What changes in concepts occur over time across conditions?
- Are the findings significant (offer new information or guidelines)?
- Will the findings be able to stand up to further testing and research?

Finally, I tried to keep in mind Shank's (2002) "seven deadly sins of qualitative research". To summarize, they are as follows:

- *The sin of competitiveness*: Trying to prove that one's qualitative study is just as good, if not better, than a quantitative study, and then putting inordinate emphasis on "quantitative-looking procedures" such as computerized data coding and analysis packages;
- *The sin of* appropriation: Doing research not for research sake but to further some agenda;
- *The sin of* rigidity: Being inflexible and refusing to give up control to participants who can guide one in the appropriate direction;
- *The sin of superficiality*: Not being curious and refusing to dig deeper to draw out more extensive and subtle insights;
- *The sin of sentimentality*: Believing that if we write up our findings with a great deal of emotion, we will be able to stir the emotions of the reader (in other words, manipulating the reader to feel a certain way);
- *The sin of narcissism*: Turning the focus toward the researcher and spending excessive time explaining who he or she is or has become;
- *The sin of timidity*: Not taking chances or exploring insights that seem to defy the norm.

Conclusion

In this chapter, I have described the research design, the method of sampling used, the use of in-depth interviews and my rationale for employing qualitative methods. I have also discussed procedures for the collection, recording and analysis of data. Ethical concerns were described and how they were addressed in this study. Finally, I explained the challenges associated with this study and my efforts to overcome them. The exploratory nature of the study allowed me to examine in-depth each participant's experience and yielded rich data. But because the study design was cross sectional and not longitudinal and it did not randomize participants and compare them with a control group, no causal relationships can be made. Self-selection could have influenced the study's findings and the small size of the sample prevents me from being able to extrapolate into the broad population of individuals bereaved by AIDS in either KwaZulu-Natal or South Africa. Despite these limitations, this study offers a descriptive investigation of individuals' experiences coping with the death of loved ones to AIDS and it is hoped that it may serve as a springboard for further research on this important issue. In the next chapter, short narrative portraits of each participant from the primary sample are presented. These are summaries or snapshots of each participant to capture the essence of who they are as well as their story.

CHAPTER 6

Study Participants

In this chapter, I introduce the 18 individuals from the primary sample who participated in this study. These profiles can serve as a point of reference as the reader moves through the analysis section. These profiles are followed by a summary of the demographic characteristics of the sample.

Profiles

***Delarise*:** Delarise turned 40 on the day of our first meeting and she exclaimed that "it was a great day, a positive day", after having conducted a successful HIV workshop earlier in the day. She had known of her HIV status for two and one half years. A Coloured woman, she was single and lived alone and had no children. She had been estranged from her family (partly because of her HIV status) and only recently were they beginning to communicate again. She possessed a teaching degree which she had never used and had worked in various administrative positions over the years. Delarise was articulate, assertive, and self-confident. She worked freelance as an HIV educator, holding workshops in both community settings as well as the corporate world. She said: "I believe I've got a story to tell and I need to tell it and I need to provide another perspective of the journey of an HIV positive person." Delarise had not experienced many losses to AIDS. However, she lost her 48 year old best friend, Mary, to AIDS two years before. Delarise still harboured mixed feelings about Mary's unwillingness to share her illness with her as well as others close to her. Delarise reported that it was Mary's "ignorance" and the way that she dealt with her diagnosis that motivated her to educate people to talk about HIV/AIDS and not to keep it secret.

***Nkosi*:** Nkosi was a lonely 25 year old Zulu male. He reported that he was HIV-negative. He had competed matric and a technical diploma but had been unemployed for some time, making ends meet with odd jobs now and then. His mother died of AIDS four years ago, yet he still grieved for her as if she had died recently - they had been extremely close to one another. Nkosi took care of his mother at home when she was dying. His father had been very abusive when he was growing up and had deserted his mother after infecting her. Nkosi and his older brother went to live with relatives after her death but were thrown out of the house soon afterward. He felt that while some people in the community prayed for him and sympathized with him for his sorrow, others were not so kind when he had cried and they had ridiculed him. Nkosi had become a "born again" Christian and was living temporarily with church elders. Although he had endured much hardship in his life, he tried to remain optimistic, relying heavily on his faith. He said: "I do things that will help me tomorrow…I don't want to waste time – ever."

***Monica*:** A 25 year old Zulu female, Monica got tested a few years ago for HIV after learning that her cousin was HIV-positive. Her cousin, with whom she was very close, died two years ago and since then Monica had also experienced the loss of her sister's three young children to AIDS. Monica was HIV-positive and had two children of her own whose HIV status was unknown. She was shy and had difficulty expressing herself. She had not finished high school and had never really held any jobs. She had lived with various boyfriends over the years that had supported her. She said: "I've learnt a lot, because they have shown me if you are a woman you depend on them." She knew which man had infected her and when she told him that she was infected, he ran away. Monica's parents were deceased and she had three sisters and two brothers who were scattered in different places. Monica helped take care of her cousin in the last months before she died. This experience had made her think about who would take care of her when she got sick, and particularly who would take care of her two children. She belonged to a support group at a hospital though she admitted she did not like to talk much about her feelings.

***Doris*:** 58 years old, Doris was a charming, compassionate, and intelligent Zulu woman. She was a retired teacher and principal, and held an Honours degree in English. She had three children: 17, 27 and 29 years of age as well as three grandchildren. She had a close knit family and she was very active in her retirement, volunteering at the church and working on a Masters degree in Communications. She had put two of her children through university by herself. Her 48 year-old husband died 10 years and although he had been sick with various ailments, his death had come as a shock. She only discovered that he had AIDS after his death. She immediately got tested and was found to be HIV-negative. Doris and her husband had problems for several years before his death as a result of his extramarital affairs. She kept silent about the cause of her husband's death for several years - no-one knew that her husband had AIDS, including her children. Then she joined a church five years ago and met people she could confide in. Today, she said she has put everything in perspective and is at peace with the past. She explained: "I am healed. I got healed when I forgave him. I only remember good things about him." A few weeks before our first meeting Doris's 60 year old brother died of AIDS. She found out that he had AIDS just before he died. None of Doris's nine siblings knew that he had AIDS and she did not intend on telling them because of her fears that they were ignorant about HIV/AIDS and that they would probably cause problems for his wife.

***Mthoko*:** 33 years old, Mthoko, a Zulu male, tested positive after his brother died of AIDS just over a year ago. His brother who was an alcoholic tried to commit suicide the year before his death. His brother had a baby who died just before he did and the baby's mother died shortly after the brother – both from AIDS. He was a quiet, introspective, and sensitive man who clearly was struggling to deal with both his brother's death as well as his own diagnosis. Mthoko was grateful for the opportunity to talk about his feelings. He was one of the saddest individuals I interviewed. He was unemployed and lived with his mother and sister. He had completed matric as well as some courses toward an engineering diploma. Although some of his six siblings knew of his HIV status, he had not told his mother because he was concerned about the effect it would have on her. He suspected that two of his sisters were infected as well. He did not have a girlfriend at the present time. Mthoko did not trust many people and appeared despondent even though he tried to sound optimistic about the future. As a result of the deaths he had witnessed, both with his brother as well as among peers, he realized that: "to live genuinely is very important...."

Prudence: Prudence, a 25 year old Zulu woman, had been with the same man for five years. She discovered she was HIV-positive in 2001 shortly after giving birth to their son. Her baby died at four months of age from AIDS. Although she had earned a diploma in business management, she had difficulty finding a job. She was presently unemployed and lived with her mother and stepfather. Her boyfriend who worked in the prisons also helped her financially. She had two younger step-siblings. Prudence was open and honest in our meetings and deeply mourned the loss of her baby. She told me: "I have lost the most important thing in my life. Now I do not fear anything. I just take life as it is." She became pregnant again with the same man and gave birth to another boy who is now 14 months old. So far, he has tested HIV-negative. Prudence is close to her mother and admires her compassion and generosity. Her mother has taken in several people sick with AIDS and taken care of them, even though her family struggles to make ends meet. Prudence said that her son and her mother keep her going. She hoped to get married soon. She was determined to live her life and not "waste the years."

***Azon*:** At 49, Azon was an HIV-positive Zulu man who had lost his wife to AIDS six months ago. They had been separated for five years but remained civil with one another. Azon's life had been one of extreme hardship. Abandoned at five years of age, he was left to fend for himself at an early age. He had worked at a store for the past 20 years and earned a decent income. He had two teenage daughters who lived with a relative. Azon had been very ill for several years. His health had deteriorated drastically recently and he said that he was ready to give up two months ago. At the time of our meeting, he said that he was feeling better and was back at work. He did not know his wife had AIDS until shortly before she died. He had not told her either about his own HIV status. Personable and self-reliant, Azon was a loner and had difficulty talking about himself. His colleagues at his workplace knew about his HIV status and were supportive. His greatest worry was his daughters and what would happen to them if he died. Azon was a very sick man who was desperately trying to live a normal life. Sadly, Azon died a few months after our last meeting.

***Zanele*:** A sweet, gentle, likeable Zulu woman who looked older than her 42 years. She was desperately poor and struggled on a daily basis to feed her six children who lived with her and her mother in a small house. Her husband left her when he found out that she was HIV-positive a few years back. She had little formal education and we conducted our meetings with the assistance of a translator. I knew we had established a bond by the end of our meetings when she tried to reply in English. I was moved by this gesture. Zanele lost one sister to AIDS in 1999 and another, the youngest, last year. Another sister died in 2000 but it was not AIDS-related, apparently. Zanele belonged to a sewing group connected with a NGO for people with HIV/AIDS and earned some money doing this but not nearly enough to live on. She relied on a government grant for two of her children and reported that most people in her community were no longer willing or able to help her. Zanele was emotionally and physically drained and trying hard to keep despair away. It was hard to comprehend how someone could survive in the midst of so much hardship and tragedy – especially with so little support.

***Felicity*:** 31 years old. A pleasant, self-assured Zulu woman, Felicity was happily married to a public health nurse and worked as a volunteer at a church that provided support services for people with HIV/AIDS. After matric, she had worked for several years at various hair salons. She lost her best friend ("sister") to AIDS four months before our meeting. She was a 42 year old single mother who refused to acknowledge that she had AIDS, even as she lay dying in a hospice with Felicity by her side. No-one in her family knew that she had AIDS until they saw the death certificate. Felicity believed that her friend may have died quickly because: "she was ashamed to be at (name of the hospice) because it was a place for people who also have AIDS." Felicity was respectful of her friend's desire for secrecy and understood why she was like that considering the way society was. Though she missed her a lot, she felt that she had gotten over her grief. She said: "I understand that she won't come back to life and life has to go on."

***Phumzile*:** A beautiful, cheerful Zulu woman, Phumzile was 19 years old. She lost her mother and stepfather to AIDS four years ago. Her younger sister who was 15 years old was now living with a boyfriend and Phumzile was living alone. She had recently broken up with her abusive boyfriend of three years. Two years ago he discovered that he was HIV-positive and Phumzile decided to get tested too. She tested HIV-positive and her boyfriend immediately blamed her for infecting him. She had just gotten a job as a receptionist at a hospital when we met. Phumzile had to watch both her parents die of AIDS when she was 15 and she has had to take care of herself since then, without any support from her extended family. In fact, they had been nasty to her and jealous of her strong will and how she had handled life so far. She said: "...they know the hell I have gone through and I am still surviving...." Phumzile radiated a need to be loved and taken care of. At one point, she asked me: "I want you to be honest with me. Do you think that I still stand a chance of me one day having my own children and my own husband?" She gravitated toward older men and acknowledged that they were like father figures and that she relied on them for financial support.

***Nomusa*:** Nomusa, a 30 year old Zulu woman discovered that she was HIV-positive when she was 21. This was six months after her daughter was born. The child died of AIDS two years ago when she was nine years old, after a long struggle with the illness. Nomusa focused on the positive memories of her daughter. She remembered her outgoing and charming personality and how smart she was. Whenever her daughter was in the hospital she said: "I could see that they truly loved her." Her daughter died a few months before the father. He had not been close to the child and had not helped raise her. Nomusa's parents were deceased and she lived with one of her brother's and his wife in her parent's house. They had made life miserable for Nomusa as she struggled to care for her sick daughter over the years. Yet, she had nowhere to go. Relations improved a bit recently when Nomusa got a part-time job and had some money. She was still burning with resentment about the way they had treated her and her two children in the past. She had been seeing a man for several years and had a baby with him, a girl, who was also HIV-positive. The child, now five years old, was responding well to ARV treatment. Nomusa's world revolved around her daughter and she remained upbeat about the future.

Sizakele: A 45 year old Zulu woman, Sizakele was highly intelligent with a strong personality that belied the many hurts she had experienced in her life. She found out that she was HIV-positive in 2001. She had suffered the loss of several close family members to AIDS including two sisters and one brother. She had three children who were HIV-negative and she was very unhappy in her marriage. Her husband, also HIV-positive, was abusive and an alcoholic. Sizakele was perhaps the most articulate, open and smartest participant that I interviewed. She was fully aware of the many unresolved issues that continued to burden her. Her main concern, like most participants, was making ends meet. She had finished matric and held clerical positions over the years. She worked odd jobs and also sold food. There was no doubt that Sizakele was a leader and that she had a lot of untapped potential to succeed in a professional career – if things had turned out differently. She said that the most "painful" loss was that of her sister-in-law to AIDS last year. They had not been particularly close in the past but when her sister-in-law discovered that she was dying, it was Sizakele who she called first, and this gesture dissolved the problems from the past. Sizakele ended up being the person who took care of her in her final days.

***Tuli*:** Tuli was a 42 year old Zulu female. She had never married and had no children. She was HIV-negative. She was very reserved at first and acknowledged having difficulty trusting people all her life – especially men. She admitted during our meeting that she had prepared herself by not intending to open up too much. She said: "When I came here, I knew what I was going to tell you…things that were general." Fortunately, she ultimately relaxed and she revealed a lot of painful feelings that she had kept hidden for some time. Her somewhat stern demeanor masked a sensitive and lonely person. She had worked as a secondary school teacher for many years but was currently unemployed after transferring to be closer to her mother. Tuli lost her 25 year old sister to AIDS three years ago. She left behind a daughter who is now five years old and whose status is unknown. Tuli worried that the child may be HIV-positive. Tuli has another sister who lives with her mother while Tuli lives alone. Her sister's death had made her even more suspicious of men and she had resigned herself to being alone because she could not risk becoming infected. She was angry with her surviving sister who "talks about boyfriends and going out and sleeping over."

Ragani**:** Ragani was a smart, personable Indian woman who looked younger than her 36 years. She worked as a project administrator for a medical research company and was studying for a law degree. She was HIV-negative. She experienced three losses to AIDS within her immediate family: her brother in 1996, his wife in 1998 and their daughter in 2002. Her sister-in-law found out that she and her one year old child were infected the day before her husband died. Ragani assumed total responsibility for the infected child and her three siblings (all girls) after their mother died. To a large extent, she had been forced to put her own life on hold, but she had come to terms with this over time. The other girls were found to be HIV-negative. Ragani did not have any children of her own. She had been particularly close to the child who was infected, and the little girl died in her arms at home. Ragani vividly recalled the horrific final days of her brother, sister-in-law and her niece and said: "I would never want anyone to go through something like this…dying is one thing, but the suffering was bad for all three." Ragani lived with her mother and the girls as well as with an alcoholic brother. She had been dating a man for several years now and was just beginning to move on with life, trying to maintain a healthy balance between the burden that had been placed on her and her desire for a life of her own.

Bathokho**:** Aged 28, Bathokho had been diagnosed with HIV two years previously, after being ill for some time. She was tested shortly after her older sister and her four month old baby succumbed to AIDS. Bathokho was frail and aware of just how sick she was. She was the sickest of all the people that I interviewed. She could not think too far into the future and said: " I have been sick for two years…I don't know if in two years I will still be alive." Bathokho was very weak and spoke in a whisper during our meetings, but she insisted that we not stop as she wanted to share her story. She had a 10 year old daughter whose father had died several years before, but not of AIDS. She lived with her mother, younger sister, her daughter and three other family members. Bathokho's daughter did not know that her mother had AIDS. Bathokho lost her job last year and the fact that she was unemployed as well as so sick, made her very depressed. She was bitter that all the sacrifice and hard work she had put into getting a diploma in human resources had been a waste of time, now being too ill too work and not being able to find a job anyway. Bathokho was prepared for the worst yet trying to hang on for her daughter's sake. She summed up her philosophy about life as follows: "You must expect everything...and hope."

***Sibusiso*:** At 25, Sibusiso was a friendly though immature Zulu man. He had lost his mother to AIDS in 1998 and his mother's sister in 2002. Most recently, he had lost his brother to AIDS. Sibusiso decided to get tested after learning about his brother's HIV status and he was not surprised to learn that he was HIV-positive, having played the field for many years. He had five children, all with different women. He said he was "celebrating" the day before our first meeting, as it was exactly one year ago that he tested positive. His brother who was 29 years old left behind a girlfriend who was HIV-positive and two children whose HIV status was unknown. Sibusiso had never held a full-time job since completing matric in 1999. He was not supporting any of his children as he was unemployed. He relied on a stipend he received for volunteering at an advocacy organization for people with HIV/AIDS. He lived with eight other family members. His grief over the loss of his brother and several other family members was offset by his attempt to maintain a carefree attitude toward life. He prided himself on being open about his HIV status – and the service this was providing. His naiveté was demonstrated by statements such as: "I once told my mother that one day I'll be a star. One day, I'll be a legend of HIV/AIDS by disclosing." His current girlfriend, who seemed to share similar personality traits, was also HIV-positive. Sibusiso admitted that he sometimes "forgot" to use condoms.

Besta: A soft-spoken, kind, middle-aged Zulu woman, Besta and her husband were both HIV-positive. She took care of her three grandchildren who lived with her. She suspected that there were many in her family who were also infected because a number of them were sick. Her most recent loss was her brother's son and she had cared for him up until his death. Bester was a home care worker for a NGO for people with HIV/AIDS and she received a parcel of food each month for doing this work. She only completed second grade and her life had been a constant struggle yet she was known in her community as someone who was always willing to visit someone who was sick and take care of them. She looked like someone who carried the world on her shoulders. She radiated gentleness, compassion, and responsibility. The stress she was constantly under was taking a toll on her health and she worried a lot. She was pessimistic about not only her future but the future of her family and the young people in her community. She felt she was surrounded by illness and death and things were not likely to change. My meetings with Besta were conducted with the help of a translator.

Nomzamo**:** I also used a translator for interviewing Nomzamo. She was a 32 year old Zulu woman who found out she was HIV-positive in 1999. She had lost two sisters to AIDS; one in 2000 and another in 2002. The sisters had left behind a total of seven children who were taken in by a brother. Nomzamo and her four children lived with her sister and her family. Her children ranged in age from 3 to 17 years. None of her children's fathers had provided any form of support, so life had been hard to say the least. She was very afraid of what would happen to her children when she was gone. She felt closest to her sister with whom she was living and she relied on her heavily for support. Other than that, she felt alone and her life revolved around dealing with being sick and trying to care for her children with minimal resources. She remained shy and somewhat timid throughout our interview and hesitated when asked for her opinions on things.

Demographic data

Table 6.1 shows the demographic characteristics of the 18 individuals who participated in this study. The mean age of participants was 35 years - the youngest being 19 years old and the oldest was 58 years old. Fourteen (78%) participants were female, 16 (90%) were Black, and thirteen (72%) were HIV-positive. The median time since they learnt that they were HIV-positive was 3.5 years. One participant found out that she was HIV-positive as early as 1993 while three participants discovered their HIV status about one year previously. Most participants were very poor and struggled to get by on a daily basis while caring for their children. Only four (22%) participants reported incomes of more than R3,000 a month. The vast majority of participants received less than R1,000 per month, either through odd jobs or grants. Two thirds (66%) of participants had children. Most participants depended on others for the basic necessities and typically lived with other family members in large households where one or two members (usually an elderly woman) supported everyone. Most participants had tried desperately to find full-time jobs but were unsuccessful and had more or less given up.

Table 6.1 Demographic characteristics of participants (n = 18)

	N	*(%)*
Gender		
Male	4	(22)
Female	14	(78)
Ethnicity		
Black	16	(90)
Indian	1	(5)
Coloured	1	(5)
Marital status		
Single	8	(45)
Married	3	(16)
Partnered	7	(39)
Number of children		
None	6	(33)
1-2	7	(33)
3-4	3	(12)
5 or more	2	(12)
HIV status		
Positive	13	(72)
Negative	5	(28)
Education		
Diploma or degree	5	(28)
Matric	5	(28)
Some high school	5	(28)
Less than high school	3	(16)
Religion		
Christian*	15	(83)
Catholic	2	(12)
Hindu	1	(5)

* Fifteen participants simply identified themselves as "Christian" without specifically mentioning a particular denomination (e.g., Methodist).

Table 6.2 identifies the relationship to the people who died of AIDS. In several cases, a participant reported more than one significant loss to AIDS. Two participants lost two sisters each to AIDS and one participant lost her husband and a brother. One participant lost both parents to the disease. One participant lost two sisters as well as a brother to AIDS. The average time since the person had died was two years and nine months. One participant experienced the oldest as well as the most recent loss among all participants: one loss was 10 years ago and the other was 1 month ago. It should also be noted that several participants experienced multiple losses but they had not been extremely close to these individuals, so they are not reported in the table.

Table 6.2 Loved ones who died of AIDS

Person/s who died	*N*
Best friend	2
Mother	1
Cousin	1
Husband and brother	1
Brother, sister-in-law and child	2
Son	1
Wife	1
2 sisters	1
Mother and stepfather	1
Husband and daughter	1
2 sisters and 1 brother	1
Sister	2
Brother	1
Nephew	1
3 sisters	1

Conclusion

This chapter summarized the life stories of the 18 participants from the primary sample. Most of them had experienced much hardship in life, in addition to losing loved ones to AIDS. Most came from impoverished backgrounds and many were coping with being HIV-infected themselves. The time since the loss varied from a few weeks to several years. As we shall see in the following chapters, a common denominator among participants was the challenge of juggling multiple life stresses while coping with the loss of a loved one. The next section explores their lives in much more detail. What follows is a detailed description and analysis of thematic categories that emerged during the interviews. Participants' own words were incorporated, whenever possible, to highlight the essence of each thematic category.

PART FOUR: ANALYSIS AND DISCUSSION

CHAPTER 7

Poverty

In this chapter, I focus on the daily living conditions of participants and the central role that poverty played in their lives. I also discuss the socio-economic impact of AIDS-related deaths on households. Unlike the US and other developed countries, people affected by AIDS in South Africa have to deal with extreme economic hardship on a daily basis. The main point of this chapter is to show how participants' emotional response to AIDS-related loss was frequently overshadowed by their daily survival needs.

The Social and Economic Context of AIDS

Crothers (2001) argued that more attention needs to be paid to examining the consequences of AIDS on South African society: "Treatment of consequences deserves at least as much coverage as that focusing on the acquisition of the infection" (p. 19). Despite the relative dearth of studies assessing the societal impact of AIDS in South Africa, it is increasingly clear that the epidemic is having dire social and economic consequences at several levels, from the macro and community levels to the family and individual levels (Gilbert & Walker, 2002a). Here is a current snapshot of the impact of the AIDS epidemic in South Africa:

- The government (very reluctantly) is faced with the cost of providing ARV treatment to a huge population of infected people who desperately need it (Benatar, 2004).
- The economy is suffering because business companies are incurring increasing costs associated with high absenteeism (due to ill health and family bereavements), employee benefits (e.g., medical insurance), and high labour turnover (due to the death of employees from AIDS) (Hope, 2001; Goering, 2003).
- Health and welfare services on all levels from government agencies to community-based NGO's are severely overburdened (Hope, 2001; Rehle & Shisana, 2003).

- Local municipalities are running out of space to bury the dead (Wines, 2004).

Furthermore, we see the following: a substantial number of children have been orphaned by AIDS, many elderly people have been forced to become the primary caretakers of children who have lost their parents or other family members to AIDS, and households are being crippled financially due to AIDS-related illness and death.

Different Priorities for the Bereaved in South Africa

Research on AIDS-related bereavement in the Western context has paid little attention to the socio-economic impact of AIDS, probably because of the generous health and welfare support resources available to individuals infected and affected by HIV/AIDS in developed countries. Furthermore, until recently AIDS in these countries has largely affected gay men who have typically been educated, financially stable individuals with no dependents. With a rise in the number of low income people (mainly heterosexual people of colour) infected by HIV in the US, it will be interesting to see if future research identifies financial insecurity as a significant stressor influencing AIDS-related bereavement. I doubt that this will be an overarching issue for the bereaved however, because of the wealth of supportive AIDS services that exist at various levels in the US as well as the much higher per capita income of these individuals compared to those in developing countries (Demmer, 1999c). I have just completed a qualitative study of AIDS-related bereavement among 12 mainly low-income, minority women living in New York and New Jersey and a preliminary analysis supports my assumption (Demmer, *manuscript in progress*).

On the other hand, in South Africa many people affected by AIDS live in very impoverished circumstances which seem to worsen when a family member dies from AIDS. There is simply no comparison between being poor in the US and being poor in South Africa. The care and support services that exist in this country to help the poor who are most devastated by AIDS are comparatively meager, and the government is swamped by the demand for welfare support (Ewing, 2002).

Research has shown that bereavement distress is likely to be heightened when there are additional stresses such as financial hardship, unemployment, daily hassles and physical health problems (Goldblum & Erickson, 1999). Most individuals in South Africa who are grieving AIDS-related deaths face a variety of stresses such as poverty, malnutrition, poor housing conditions, and limited formal support services, unlike those who are bereaved by AIDS in developed countries. These factors make the experience of AIDS-related bereavement in South Africa quite distinct from the West. As we shall see in this chapter, the primary focus for participants was not on addressing their emotional well-being, but rather it was about trying to survive on a daily basis – dealing with health issues, finding money for food, a place to live, or figuring out ways to send their children to school.

Living Conditions

Most participants in this study were very poor and struggled to support themselves and their families. This is not unusual when one realizes that AIDS primarily affects the poorest, most disadvantaged groups in this country (Mitton, 2000). The majority of the poor in South Africa have inadequate provision of water, sanitation, electricity, and more than one third of children less than five years of age are undernourished (South African Health Review, 1999; Gilbert & Walker, 2002b). According to Poku (2001), these social and economic problems "create a particular vulnerability to the devastating consequences of the epidemic" (p. 203). South Africa is one of the most unequal societies in the world (Johnson & Budlender, 2002; UNISA, 2000). Economic power is still heavily concentrated in the hands of whites who represent about 10% of the total population (Schneider & Fassin, 2002; Gilbert & Walker, 2002b). Approximately two-thirds of black households live in poverty compared to 6.7% of white households (Gilbert & Walker, 2002b).

A study by Cunnan and Maharaj (2000) illustrated the substandard living conditions of a substantial proportion of black South Africans. They studied the living conditions of 100 households in Canaan, an informal settlement situated in the Durban Metropolitan Region. I cite this study because several participants in my study lived in areas similar to the one described by Cunnan and Maharaj (2000). Here is what they found:

- The average monthly household income was R627;

- Twenty-three percent of respondents missed meals at least twice a week and 33% said that they occasionally missed meals;
- There was no piped sewage and only one communal tap;
- Fourteen percent did not have any type of toilet facilities (not even a pit latrine);
- Thirty-percent of the dwellings did not have windows;
- Fifty-five percent of households had an individual afflicted by an illness or disease, and the most common ones were tuberculosis, a sexually transmitted disease, and asthma;
- Ten percent had not taken their children to be immunized;
- Twenty-six percent experienced problems obtaining primary heath care and the main problem was not being able to afford medical fees or travel costs to the hospital or clinic.

For most participants (even the handful who were "better off" and earned R3,000 or more per month), the constant battle to make ends meet was exhausting and made them despondent and fearful of the future. Zanele, who was probably the most impoverished of all participants, lived on a government grant of R340 a month for two of her children. She cared for six children and an elderly mother. She worried about her children "each and every day." And she tearfully admitted that sometimes they "sleep without food."

Besta always put the needs of others before her, and she said that she wished she had money so that she could send her deceased brother's son to school. When pressed to identify what she would buy for herself if she had the money, she said that she didn't have a television or a radio and that the house was "empty". She was more concerned about being able to afford food, clothing, and school fees as these were more urgent needs for her family. Right now, she felt that there was nothing she could do about her situation and this caused her to be depressed. When asked what families needed the most when someone died of AIDS, she indicated that they needed food and more money for the people who come from all over for the funeral. Besta had problems with her blood pressure which she attributed to the constant worry about money. Her husband had been sick for some time and only recently began to do some part-time jobs, and he earned about R1,000 a month which they all lived on. She said: "Most often, I worry about money…it is always so little…I am a mother and I am supposed to be responsible but it seems like I'm not and the money is wasted on a few things and then it's gone." She took care of her three grandchildren who lived with her and her husband.

While Tuli did not have any dependents, she too was very despondent about her lack of money. She received a stipend of R800 per month for a volunteer position. She felt very vulnerable as she had no-one that she could rely on to help her. Her mother was retired and her younger sister was not working. She said: "At the end of the month, when I get my R800, nothing comes out of it…I have to put on clothes, I have to eat, I have to pay for my rent." Her rent on her flat was R500 per month, which left her with R300 to live on. She said that she ate bread at the place where she volunteered.

Nkosi relied on the kindness of church elders who had taken him in temporarily. His mother had died of AIDS and his father had deserted him and his brother. His brother was living elsewhere and he rarely saw him. For two years, an elderly relative had taken care of him but she was supporting so many other family members that he had to leave after a while. He possessed few belongings and was deeply disappointed as well as frustrated that he could not continue his secondary education. Yet, he felt optimistic about the future: "I think I will get married some day. I will live in a house. I'm very confident and I know I will make it."

Prudence was living with her parents, who were both unemployed and her mother brought in a bit of money by selling food. When asked how the three of them lived on virtually nothing, she said: "I do not know. What I noticed is that if you are a giving person, God tend to give you more. I do not know how it happens, but we do live and it is a happy home…"

Even for Doris, who received a teacher's pension as well as a pension from her deceased husband, money was an issue. Even though she was certainly much better off than most of the participants, she wished that she could earn more money. She had her own flat in central Durban and her monthly income was R4,000. Two of her three daughters lived with her.

Impact of the Death/s on the Household

According to Warwick et al. (1998), it is at the household level that "the impact of HIV and AIDS is most seriously felt" (p. 313). AIDS impacts households over a long period of time, from the time the person becomes ill until way after their death (Gow and Desmond, 2002). Households tend to experience a longer period of depletion of resources when the household member has AIDS versus another illness, due to the protracted nature of the disease (Barnett, Whiteside & Desmond, 2001). According to Hope (2001):

> Having a family member living with AIDS results in a significant decrease in household income and huge rises in medical care spending. Decreased income levels lead to a decrease in consumption patterns, diminished savings and, in some instances, debt. (p. 26)

In a recent study of HIV-infected adolescents and HIV-infected parents in the North-West Province of South Africa, 20 out of the 25 parents reported negative economic effects on the household stemming from their diagnosis (Strydom & Raath, 2005).

Thirteen participants in the current study made reference to increased economic hardship both before as well as after the death of a loved one. Typically, a family member became very ill and then lost his/her job, with the result that other members of the household had to scramble to find extra money to fill the void. However, this was usually not possible, and the household sank deeper into debt. Besta who had barely any household income coming in at the present time was dealing with her own health issues as well as that of her husband. She taken it upon herself to try and assist several other family members who were sick with HIV, but she was overwhelmed by how much they needed and how little she had to offer them. She said that she did not need much for herself but that she worried constantly about her family. The economic impact of having an HIV-infected member in a household has received some, though not enough, attention by researchers. Several studies have examined the impact of AIDS-related illness and death on households in developing countries but only a handful of studies have been done in South Africa. Ewing (2002) argued that the costs to poor households affected by AIDS are often outstripped by the available resources. She added:

> This needs to be better documented and given a much higher profile. Otherwise it might appear to policymakers promoting home-based and community-based care as the only affordable option that these costs are, and will continue to be, absorbed. (p. 81)

Bachman and Booysen (2003) conducted a longitudinal study of 202 households with an HIV-infected member and a cohort of 202 unaffected households in one rural and one urban area in Free State Province. They indicated that at baseline, affected households tended to be larger, poorer and to have lower employment rates than unaffected households. Over a six month period, income and household expenditure declined more rapidly in affected households than in unaffected households. In a follow-up study of 404 households in Free State Province over 18 months, Bachmann and Booysen (2004) noted that expenditures in affected households continued to decline.

Since her brother died of AIDS, Besta had taken in his son and now she had to not only feed and clothe him, but find money for school fees. Her sense of hopelessness and despair was evident as she discussed this issue with me. She became quiet and teary, and her hands began to tremble. In Cross's (2001) study of poor, rural households in KwaZulu-Natal, the burden of incorporating children orphaned by AIDS into the household, without additional support, typically pushed the household over the edge. The education costs of the orphans were a particular drain on household finances, and this included school fees, transport to school, and school uniforms. With few options for digging their way out of poverty, households fell into a downward spiral where spending for basic needs was drastically curtailed and little money was available for food. Several participants indicated that they and their children regularly went without food. For example, Besta spoke about how it broke her heart that sometimes her children went to sleep without food.

In Ragani's case, her elder brother had been the main breadwinner in the household and when he died and then his wife shortly afterward, she had to assume this role. Not only did she have to support herself and her four nieces (one of whom had AIDS), but also her mother and occasionally her alcoholic brother who only worked sporadically. The plight of households coping with the economic impact of losing a loved one to AIDS was dealt with by Gow and Desmond (2002). They surveyed 178 households in the Bergville area of KwaZulu-Natal, and found that there was a big difference between households that had experienced a death (presumably from AIDS) in the past 12 months and those that had not. The mean household income in affected households was R848 compared to R1,330 for unaffected households, meaning that incomes in affected households were 56% less.

Participants reported that while they had relied on neighbours for support on occasion, this was no longer an option for many of them; neighbours did not want anything to do with them because they were tired of helping out. As Cross (2001) observed, households cannot continually depend on "neighbourhood charity". Participants engaged in common survival strategies such as those reported by Gow and Desmond (2002); after already borrowing from family and friends, several participants had no choice but to sell off their few assets and to ration food. This is very worrisome for two reasons. First, many participants in this study were HIV-positive and several were quite ill, and not getting adequate nourishment was detrimental to their health. And second, most participants had young children who were going hungry. It is also possible that several of the participants' children were HIV-positive, so their health too was being further compromised without adequate nutrition. When I asked Nomusa what advice she could give people who wished to help someone who had lost a loved one to AIDS, she replied: "The most obvious thing is money."

What I found interesting was that none of the participants talked about the medical costs of caring for the deceased. Perhaps it was because they did not have to pay for medical costs, as it was either covered by insurance in one or two instances or the more likely situation was that the person was treated at a public hospital. The main concern seemed to be more about losing a source of income in the household when the person became too ill to work and the challenge of having one more mouth to feed. This contrasts with research done on AIDS impacted households in Free State Province where health care costs were found to be a significant drain on household resources (Bachman

& Booysen, 2003). Similarly, in their study of households impacted by AIDS in rural Tanzania, Ngalula, Urassa, Mwaluko, Isingo and Boerma (2002) noted that exorbitant medical costs exceeded the estimated per capita annual household income of the population in this region. In both of these studies, funeral costs were also identified as a major drain on households. This issue was not mentioned by participants in the current study, however. It appeared that a number of the deceased were covered by funeral policies. Only Besta remarked that when people die the family needed money to buy food for "the people who come in and wait for the funeral."

Participants described how families became splintered upon the death of an individual and family members were relocated to other households. Nkosi said: "When my mother passed away, my father decided to just leave us there." Although no longer a child (he was 21 at the time) Nkosi and his older brother were unemployed and had nothing, so they went to live with an aunt. However, this did not work out because of friction with her sons and Nkosi and his brother separated and went their own way, living wherever they could until they were no longer welcome. Azon had been separated from his wife and when she died his two daughters moved in with an aunt who he gave money to for their upbringing. Besta took in her brother's son after he died as there was no-one else in her family to care for him. Nomzamo lost two sisters to AIDS - leaving behind a total of seven children – and they were all taken in by one brother. In Phumzile's case, she had nowhere to go, after losing both her parents to AIDS. At the time, she was only 15 years old and she was left to care for her 11 year old sister. Hosegood, McGrath, Herbst and Timaeus (2004) reported that poorer households are vulnerable to dissolution as a result of AIDS mortality. They examined the impact of adult deaths on household dissolution and migration in a rural area of northern KwaZulu-Natal. Based on data collected on households between January 2000 and October 2002, they found that 21% of households had at least one adult death. Households where one or more adult members died were four times more likely to dissolve during this time period.

Most participants in the current study discussed the difficulties of trying to keep their family together. Doris was grateful that she was able to keep her three children with her and raise them on her own after her husband died. For Ragani, being young, single and career focused, the prospect of raising three little girls, including the youngest one who was very sick with AIDS, was daunting. But she could not bear the thought of separating her brother's three girls once their mother had died. She devoted her life to the girls. Sadly, the sick child died three years later. Looking back, Ragani had no regrets about becoming the girls' "mother". Today, at age 36 years, she was starting to focus again on herself again and was pursing a degree in law.

Some participants experienced no change in their living arrangements after their loved one died. Prudence remained with her mother and stepfather after she lost her four month old baby. Bathokho, who lost a sister, continued living with her parents who were helping her to raise Bathokho's daughter now that she was too ill to do it herself. Nomusa had lived with her brother and sister-in-law throughout her young daughter's illness and tolerated their hostility toward her and her child (both being HIV-positive). After her daughter died at nine years of age, she continued living with them and raising her other daughter who also was HIV-positive. She had nowhere else to live, but she said that things were better now between her and her brother (probably because she was bringing a little bit of money into the household).

Burden Borne by Women

A dominant theme in my interviews was the central role women played in caring for the sick as well as dealing with the aftermath of a death. But this is not new information. Barnett, Whiteside, and Desmond (2001) indicated that females in Africa are more harshly affected by the epidemic, as they "may be less well nourished or removed from school to save money for care costs of a sick parent, through to stigmatization on the death of a husband, and finally a lonely and impoverished widowhood" (p. 161). In a qualitative study of the impact of AIDS-related deaths on rural households in KwaZulu-Natal, Cross (2001) noted that most of the economic burden of household support was being carried by women. Women headed households were at great risk for sinking even deeper into poverty because of the shock of taking in children orphaned by AIDS as well as the fact that women had greater difficulty applying for assistance from bureaucratic organizations. Cross reported that women widowed by AIDS were often shortchanged by companies or government offices where their husbands had been employed when trying to claim death benefits. Women were often turned away or given "unrealistic low offers" and Cross noted further:

> It was the least educated and poorest women who were the most vulnerable to strategies of bureaucratic denial or delays – men in the same situation may have been more forceful or better informed, and seemed to have fewer difficulties. (p. 146)

Women are also more vulnerable when it comes to land rights (i.e., the rules governing how land is held, used and sold). In a study of the impact of HIV/AIDS on land issues, Drimie (2003) reported that "HIV/AIDS may affect the ability of widows, orphans, and youth to access and use land, transact or inherit it, to exclude others from it, or to ensure that their rights are enforced" (pp. 653-654). Case studies from four areas of KwaZulu-Natal (Dondotha, KwaDumisa, KwaNyuswa, Muden) revealed that women and orphans were vulnerable to losing their land rights. Traditional cultural norms in areas of KwaZulu-Natal dictate that women generally do not have land rights independent of their husband, and when the husband dies the woman remains in possession of the land at the will of the extended family (Drimie, 2003). In the case studies, the land rights of women and orphans were usually arbitrated by traditional authorities within a "framework of a patriarchal system that often upheld gender inequalities" (p. 657).

Sizakele had the primary responsibility of supporting her family. Her alcoholic husband was of little help, squandering what little money he earned now and again. Sizakele got very down about not having enough money to make ends meet. A big stressor was finding money to pay for school fees, which were approximately R800 per month. She was saddened and despondent that her two children in high school often were called into the office because she had not paid the school fees. She sold food (baked goods), and if she was lucky, she earned about R1,500 per month doing that, and the whole family survived on that amount. She was overwhelmed by debt and felt that she was letting her children down. She owed R5,000 on back rent and her eldest son had to drop out of his first year at technical college because she could not afford the tuition. Her sense of failure as a parent was obvious: "My youngest son says, 'Every morning, by the time I go to school, you are no longer at home -you are working. But at the end of the month, there is no income. I don't really understand how you do this'"

Participants mentioned that they seldom received support from males, either in caring for the deceased or the deceased's children. Both Zanele and Sizakele had lost sisters to AIDS and they all left behind children who were sent to other female members who assumed responsibility for them. The fathers of these children were absent from the picture. Zanele was struggling to raise her own six children and had gone to court to see if she could get the father of her children to support them, but to no avail. They had told her that they could not help her "because it is not easy to find where he stays and where he works." She was depressed because she had nothing to cook for her children. Nomusa was left to raise her HIV-positive daughter on her own until the child died at age nine – the father had only occasionally given her money. Monica was desperately poor and relied on food parcels and boyfriends to support her and her children. She and her children lived with an elderly aunt. She had been very dependent on a boyfriend who she subsequently found out had infected her, and then he ran away. She said: "He was like my father, he was like my mother...because he took care of me and my brothers...I was so worried when he ran away because there was nobody that could do that thing..." Phumzile, at 19 years old, continued to seek out older men or father figures, who would give her money. She added: "It makes me feel kind of protected if he's older than me." When I talked to Delarise about how it seemed that women were dependent on men for money to care for their children, she replied harshly: "Then they shouldn't be poor if the men are providing." She said the situation was rather one where women were "not getting the payment." When I asked Sizakele why women put up with men who were unsupportive, she replied simply: "It is not easy." When I asked her if it was true that women hoped to find a man who would take care of them and that was why they were willing to put up with "nonsense", she was uncertain: "Yes, I suppose so, and not. Because, it's not all men that one falls for that has so much of riches. I don't know."

Nkosi, a single man, agreed there was a difference in the way men and women approached AIDS in South Africa. He said: "Men are like cowards...when they face this thing, they just run." Phumzile echoed something similar: "Men are cowards! They just run away. They run away from reality. They are so in denial!" Nomusa was at a loss to explain this state of affairs:

> (Sigh) I just don't know. I really don't know what happens or what goes wrong with them. Actually, I am failing to understand the reason why...Men are ignorant, I don't know why – I just don't know why. They seem to be the same –all of them.

Sibusiso did not support his family. He displayed a very machismo attitude about caring for his own children. At 25 years old, he was HIV-positive and had never held a full-time job. A healthy, good-looking man, he had no trouble finding women to have sex with and he had five children, all with different women. He only worried about his one year old son, "because he is still very young...I am so fond of him...He is depending on me, I have to have cash...everything revolves around him..." Although he claimed to feel guilty about his inability to provide for his son (not mentioning his other four children), Sibusiso was seriously considering giving in to his current girlfriend's wish to have his child. When asked if he practiced safer sex, he hesitated and said: "I'll be perfectly honest; we didn't practice safe sex for the first time because she wants my baby..." Did he use condoms the last time they had sex? He replied: "The last time, we didn't...we have to practice safer sex – practice what we preach...but we are all human." When asked what his plans were regarding getting married to her, he responded:

> Right now, I want to know my finances. I want to change, even though I have very little. I want to make sure that she helps me with my finances. Maybe, one day we could be together...Sometimes, I feel I am wasting my time with her. She expects too much from me when I am around her. She wants all my attention.

Incidentally, Sibusiso was still having sex with the mother of his last child and he claimed that his girlfriend knew this: "She knows. I told her I have five kids and I am still seeing the other one...She is ok with it."

Interviewer: "Is she seeing someone else too?"

Sibusiso: "No, she is just with me. Whenever I need to see her, she makes sure she doesn't disappoint me."

Interviewer: "How would you deal with it if she was seeing someone else as well?"

Sibusiso: "I will make her choose. I will not compromise with her."

But clearly not all men are like Sibusiso. Azon did not have time for relationships and focused on his job and earning as much as he could so he could continue to support his two daughters while he was still relatively healthy. When Azon, who was more financially better off than most of the other participants - earning about R3,000 a month, was asked what made him happy, he replied: "Nothing at the moment. I'm always thinking about money." He was very responsible with his money and most of it he sent to his aunt. When I asked him what he would do for himself if he had more money, he replied: "I would take care of myself (medically), and put my kids in better schools…" He remarked that he had no time for fun, as his life was just work.

The Elderly

During my interviews with participants, I began to wonder about the effect of AIDS-related deaths on parents who were elderly. Mthokho lived with his elderly mother and I was curious about what it must have been like for his mother to lose a son as well as a grandchild to AIDS, and now she had to support another son (Mthoko) who was HIV-positive and unemployed. Similarly, what was going on with Bathokho's mother who had lost a daughter to AIDS and was now supporting another HIV-positive daughter in addition to a granddaughter. And what about Ragani's mother who had lost her son, daughter-in-law and grandchild to AIDS? And then you had Prudence's mother who took care of Prudence and her infant son before he died and now she had another child of

Prudence's to worry about. I knew that these were voices that also needed to be heard – middle-aged and elderly mothers who had lost adult children and in some cases grandchildren as well. How were they coping while continuing to support other family members at the same time? How did they do it? Sizakele commented that there were so many grandmothers looking after children. She remarked: "Aiii. It is so difficult because most of them are very old. Grandmothers are depending on the social grant." When asked what would happen to these children when the grandmother died, she was at loss for words: "That's the biggest problem."

In looking at the research, I found that not much data exist on the impact of AIDS-related deaths on the elderly, and this applies to both developed and developing countries. Knodel and VanLandingham (2002) explained that one reason for this may be that "they are less visible and have less public appeal than other age groups, especially children" (p. S80). Nevertheless, adults who die of AIDS leave behind parents as well as children and the elderly are affected by AIDS-related loss in "profound and consequential ways" (p. S77).

In developing countries, the social, economic, and health consequences of AIDS on the elderly are magnified. Besides having to endure the pain of losing a child, elderly parents have to take on the responsibility of paying for the medical and living expenses of their sick children, care for them, pay for their funeral costs, as well as assume responsibility for their grandchildren (Knodel & VanLandingham, 2002). AIDS in Africa has also been called the "grandmother's disease" because older women are expected to care for their grandchildren as they watch their own children die (Moller, 1997). They are expected to take in children orphaned by AIDS, and to feed, house, clothe and educate them, as well as care for them if they are HIV-infected and later bury them (Williams & Tumwekwase, 2001). Because of the high number of AIDS-related deaths in Africa, many elderly people are deprived of any support in their old age that their deceased children would have provided. Furthermore, Williams and Tumwekwase noted that "to lose one's children not only means that one will not be honoured by a fitting funeral, but that there will be no-one left alive to record one's contribution to one's clan, or one's very existence" (p. 231).

In their study of the impact of AIDS on households in the Bergville area of KwaZulu-Natal, Gow and Desmond (2002) found that in households where both parents had died, it was typically the grandmother who became the primary caregiver and they cautioned:

> The reliance on grandparents to provide care after the death of parents is dangerous and will become increasingly so as the epidemic progresses. When the grandparents die these children face being orphaned again. The question of who will care for them then remains unanswered...The grandparents of the future are dying in the present. Who will care for the children in 15 years time? (p. 124)

In their study of trends in the living conditions of older Black households from 1995-1998, Moller and Devey (2003) reported that most of these households tended to be "larger, multigenerational, female-dominated and female-headed households" (p. 468). Approximately half of older Black households included three or more generations. Furthermore, these households were usually poor, located in rural areas and included large numbers of unemployed household members as well as dependents. Older Black households continued to have difficulty feeding their younger members. The state old-age pension, which was R540 in 2001, was a major source of income for the poor and it was the reason why so many households were formed around pensioners (Moller and Devey (2003). According to Knodel and VanLandingham (2002), the elderly are susceptible to additional stresses as a result of the epidemic:

> The health of older-aged parents could suffer through physical strains from care-giving, extra work taken on to pay expenses, and/or potential exposure to the opportunistic diseases (especially tuberculosis) that PHA [persons with HIV/AIDS] often contract. Older parents' social relationships may be disrupted by the time-consuming demands of care-giving. Stigma can lead parents to withdraw from normal community life or cause others to avoid socializing with them. (p. S78)

Several studies have reported on the impact of AIDS-related deaths on the physical well-being of the elderly, including studies in Zimbabwe (Mupedziswa, 1997), Thailand, (Knodel, Saengtienchai, Im-Em & VanLandingham, 2001), and Tanzania (Appleton, 2000). In Dayton and Ainsworth's (2004) longitudinal study of the elderly in Nortwestern Tanzania, the body mass index (BMI) which was used as a measure of physical well-being, declined among the elderly who were living in households with a terminally ill adult. In the US, Joslin and Harrison (2002) found that older individuals who raised children affected or orphaned by AIDS were likely to be 'hidden patients', meaning that their own health needs were neglected because of their caregiving responsibilities. They interviewed 20 caregivers (mostly grandmothers) of HIV-orphaned and-affected children and found that more than half rated their own health as 'fair' or 'poor', and 70% reported that they did not have enough time to attend to their own health.

A final point needs to be made here. While Knodel and VanLandingham (2002) have drawn attention to the limited data on the socio- economic and health effects of AIDS on the elderly, it must also be stressed that we need to learn more about the psychological impact of AIDS-related deaths on the elderly. We have very limited information on the grief reaction of the elderly in Africa. Drawing on their experience working in an AIDS research programme in Uganda, Seeley and Kajura (1995) provided an illuminating, though brief account of community grief in Uganda that was compounded by economic hardship, loneliness, stigma, and multiple losses. Williams and Tumwekwase (2001) also provided a short account of personal and community grief experienced by elderly residents of a rural, Southwestern Ugandan village.

Unemployment

More than anything, participants were obsessed with finding a job. Thirteen of the eighteen participants did not have steady employment. Unemployment is rife in South Africa: even though South Africa is classified as a middle-income country by the World Bank, about 40% of the workforce is unemployed (Gilbert & Walker, 2002b). Several participants held post-secondary qualifications and a number had completed matric, but they struggled to find even a part-time job.

Mthoko said that the biggest concern for his family was "to get some of us employed. It's going to happen, but just waiting is tough." He was optimistic about the future though: "I do believe that as time goes on, we will have a better income." He had completed part of an engineering diploma and then had to stop his studies and return home because his family had no money. He said: "I came back disappointed but I realized that what God has planned is not finished."

Prudence, who was overjoyed to be starting a full-time job in the following month, said that her biggest concern in life had been "for me to get a job." When asked why it was so important, she replied: "For life to go on, you need to have some money. Everything is money in this world. I have to raise a son." Prudence felt cheated because she had not been able to achieve certain material goals. She explained:

> I love cars. When I was growing up, I told myself that when I reach 25 I will be driving my own car, and now it is not happening and I am HIV-positive – whooh! I have become very bitter about that. I did not plan to be HIV-positive but it has happened...My two cousins went to college together – now they are driving their own cars and we are all 25 years old. When I look around, I say, hmmm, I wonder what is happening to me?

For some participants, a job was desired in order to have more money, but for several HIV-positive participants getting a job meant something more. It signified a new life and hope for the future for Phumzile, it meant freedom for Nomusa who would no longer need to live with nasty relatives, and it was a final last wish for Bathokho who felt that she was nearing the end of her life and she needed to have something to show for it.

Phumzile, at 19 years old and HIV-positive, had recently found a job as a receptionist and this had been a major boost to her spirits, giving her hope for the future which she felt she sorely needed. Nomusa's biggest goal was to get a job: "Because that that is where life begins. You are able to be on your own." Bathoko, who was 25 and very ill, depended on her mother after losing her job a year ago. There were eight people in the household and they all relied on income from Bathoko's mother and sister which was about R2,100 a month. Bathoko was able to pay her daughter's private school fees of

R15,800 last year when she was working but now she was too sick and unable to work, so she could not afford it. Although she realized that she was too weak to work, she still fantasized about getting a job and using her diploma in human resources that she had worked very hard to obtain. She commented:

> All I am worried about now is to get a job. That's my biggest worry...Sometimes I feel I am too weak...though if I could have a phone call just saying I got a job - that would be great – even though I'm feeling very weak.

Welfare Support

In the US, people with HIV/AIDS can qualify for a variety of services and benefits including medical care and ARV drugs, monthly financial support (social security), food stamps, and case management services from a variety of community-based organizations including help with housing, psychological support and even recreational services. I wrote about my experiences running an AIDS service organization in the 1990s in the South Bronx of New York (Demmer, 1999c). One of my staff's biggest challenges was to actually "interest" clients in our services, so that they could take advantage of what was offered to them. In New York City alone, there were estimated to be 166 AIDS service organizations between 1981 and 1998, so people with HIV and their loved ones in the US have lots of services to choose from, most of which are provided free of charge (Chambre, 1999). In contrast, welfare support for people with HIV/AIDS and their families in South Africa is extremely limited. Some HIV-positive participants mentioned that they participated in a HIV/AIDS support group at a local hospital or organization and found this to be very helpful. A number of participants relied on food parcels from various NGOs and occasionally some were given stipends from NGOs for doing volunteer work. Some, like Nomzamo and Zanele received government grants for their children, and the entire family lived off this money.

Delarise, a single woman with HIV and an HIV/AIDS educator, felt that the welfare system in South Africa was being abused by people claiming to be affected by the epidemic. She felt that many women were taking advantage of the system and had themselves to blame for their predicament. Here is what she said:

> I stood in the post office one day and...I wondered why there were all these queues out of the post office. I'm a curious person so I asked the guy, 'Why are all these ladies here?' 'Oh, they're here for child maintenance'. I said, 'Oh, but why are there only Black ladies? Why aren't there other race groups here?' So then I started talking to all these ladies. Some of them have three and four children and they have dumped these children. So you hear the stories about AIDS orphans but they're not really AIDS orphans. These women have dumped their children and nobody is checking what this money is for. So these children are abandoned all over the place while these women continue to make money out of all these "AIDS babies" and the government doesn't want to address over-population....We have the democracy. All they do now is continue to make babies. HIV is all over the show – they're poverty-stricken, they can't afford it, and yet the only recreation is sex. So I don't buy this Africa's victim role. Whenever you see Sudan, it's always a woman with two to three babies around her. If we talk about culture and tradition, don't they see that culture and tradition are not working for them because they are being abandoned by these men who left them with all these kids. There is no food, so why are they still having their next baby? Why aren't community workers going into these rural areas to educate these people about contraception. So I don't buy that!

Granted, there are people taking advantage of the system, but to any practitioner working with people affected by HIV/AIDS in South Africa, there is no doubt that there is a lot of unmet need. Up to this point, the South African social welfare system has been unable to adequately meet the basic needs of those affected by the epidemic. Many individuals (including children) who are trying to cope with their loss must summon the energy and determination to embark on the often frustrating and draining process of applying for minimal government benefits. It can take an extremely long time (sometimes up to several years) to process welfare applications, and the lack of appropriate documentation (birth and death certificates, identity documents) prevents many people from applying for and receiving welfare support (Walker, Reid & Cornell, 2004). This can be a life or death situation for some bereaved families who have no food or shelter. More than five million children regularly go hungry and at most, only 12% of the poor children in South Africa receive child-support grants (less than R200 a month) (Walker, Reid and Cornell, 2004). Many children orphaned by AIDS must head households and take care of their siblings without help because if they are under 21 years of age they cannot qualify for grants as the primary care-giver. (Walker, Reid & Cornell, 2004).

Conclusion

AIDS-related deaths push many poor households over the edge into deep poverty, forcing the bereaved to desperately find ways to sustain themselves and other household members while simultaneously coping with the pain of their loss. The high prevalence of AIDS-related deaths has major social and economic consequences for South Africa. On the micro level, individuals, households, and communities are being pushed to the limit trying to cope with the economic implications of losing the breadwinner to AIDS, and the government's continued expectation that households and community members take care of one another is unreasonable. Women, children and the elderly are bearing the brunt of AIDS-related mortality and government assistance for these vulnerable groups is woefully inadequate. In the next chapter, I expand on the plight of children in the AIDS epidemic and discuss participants' concerns for children in their community whose parents have died as well as their concerns about what will happen to their own children when they die.

CHAPTER 8

Children

This chapter describes the plight of children who have been affected by the AIDS epidemic in South Africa and examines participants' concerns about the welfare of children. Several participants spoke on the subject of children (both their own as well as the children of the deceased). Their concerns revolved around two issues: the fate of the deceased's children and fears of what would happen to their own children once they died (in the case of participants who were HIV-positive).

Children Bereaved by AIDS

A total of six participants spoke about the loss of a loved/s to AIDS who left behind children who were now orphans. Zanele, Sizakele, Tuli, and Nomzamo all lost sisters who had children, and Delarise and Felicity both lost a best friend who had children. In each case, the fathers were out of the picture. In one case, the children witnessed the loss of both parents to AIDS. At the time of death, the priority was for family members to take in the children and to keep them together. Participants noted how much of a struggle it was for these families to accommodate the deceased's children into already overburdened households and how it strained material resources. But only two participants knew first-hand what the experience was like. Besta took in her brother's son and Ragani took in her three nieces after her brother and his wife died.

In South Africa, AIDS has left many children without parents. At the end of 2001, there were approximately 666,000 children under the age of 15 years orphaned by AIDS in South Africa (UNAIDS, 2002). This is compared to 420,000 at the end of 1999 (UNAIDS, 2000). Considerably more children have been orphaned by AIDS in South Africa than in the US for instance which has a total population about six times that of South Africa. A recent report indicated that through 1998 there were 97,376 children left motherless by AIDS in the US (Lee & Fleming, 2003). On the other hand, in South Africa, it is projected that there will be more than 2.5 million children orphaned by AIDS by 2010 (Rehle & Shisana, 2003). A lower estimate was projected by Johnson and Dorrington (2001) who indicated that without ARV treatment the number of children who will lose a parent to AIDS will peak at 1.85 million in 2015. The vast majority of these children are Black and this trend will likely continue into the future. Johnson and Dorrington (2001) asserted that national implementation of ARV treatment programmes could significantly reduce the number of orphans in the next 15 years. We can only hope.

Recently, the Human Sciences Research Council published a report using data collected for the 2002 National Household Survey (Brookes, Shisana, & Richter, 2004) that highlighted the vulnerability of children in South African society. The report included information on orphanhood and risk factors for HIV infection among a sample of 3,988 children. The following findings were reported:

- 15% of children had lost a parent/caregiver by the age of 14 years.
- 25% of children 15-18 years of age had lost at least one parent/caregiver.
- Children of African descent, children in poor households, and children living in informal settlements were more impacted by AIDS.
- 0.5 % of households were headed by a child between 4 and 18 years of age.
- 45% of children lived in homes where there was not enough money for food and clothing.
- Almost one third of children were exposed to someone in the household and neighbourhood who got drunk regularly.

The authors of the report recommended that further research be conducted to assess orphanhood and to examine child-headed households due to HIV/AIDS. In the interim, they concluded that care and protection of children at home and in school was inadequate and this together with the combination of poverty and exposure to alcohol was creating an environment where children could be at considerable risk for sexual abuse and consequently HIV infection. For example, one third of children were left at home in the care of a person 15 years or younger, most children traveled on foot to school with little adult protection, and 50% of children 2 to 11 years of age were sent out of the home alone on errands (Brookes, Shisana, & Richter, 2004).

The plight of children orphaned by AIDS in Africa has received quite a good deal of attention in the popular press, and to some extent in scholarly journals. But, to date, there has been little systematic, empirical research to investigate the experiences of these children (Wild, 2001, Bray, 2003). Journal articles have tended to be either reviews, prevalence studies of orphanhood due to AIDS, or discussions of policy implications. Barnett, Whiteside, and Desmond (2001) noted that Susan Hunter was one of the first scholars to conduct empirical research in African countries on children orphaned by AIDS. Few books have been published on this subject, but two books deserve mention and they are Emma Guest's *Children of AIDS* (2001) which focuses on Africa's orphan crisis and describes the experiences of orphans, caregivers and health workers in, and the other is by Jeff Gow and Chris Desmond titled *Impacts and Interventions: The HIV/AIDS Epidemic and the Children of South Africa* (2002) which describes the impacts of the HIV/AIDS epidemic on children in South Africa as well as the various responses to this crisis. Both books were published by the University of Natal Press, incidentally.

Let me focus briefly on Guest's book. This was one of the first books to record the experiences of children orphaned by AIDS in Africa. To the uninitiated, it offers a glimpse into their lives and their struggle to survive amidst extreme poverty and this is done through a collection of true stories of families, children, caregivers, social workers, and international workers. The author focused on three countries: South Africa, Uganda, and Zambia. In the introduction, the author presents a realistic and critical assessment of the state of AIDS in Africa and the way it is being addressed. The book is divided into four sections. The first section contains stories of a grandmother, an aunt, and a white couple who battle the bureaucracy to become foster parents to a Black AIDS orphan. The story of Mrs Banda, the grandmother, is heart-wrenching. She is quoted as saying:

> I nursed my children until the illness got really bad and I couldn't cope any more. Then I took them to the hospital where they died. They were dying – one, two, three, four, five – in the order they were born. But, you know, I can't remember how old they were when they died. I keep forgetting things. (p. 19)

She is caring for eight grandchildren and her biggest problem is getting enough food for them. One wonders how anyone can survive after shouldering this amount of grief let alone also having to care for so many young lives with no resources or support. The next section of the book focuses on community workers and social workers and their efforts to help these children. One chapter describes the difficulties facing workers in the child welfare system in South Africa (mainly lack of funds and nonsensical government policies). Other noteworthy chapters in this section of the book describe a "cluster' foster home for orphaned and abandoned children in KwaZulu-Natal and an orphanage for HIV-positive children in Crossroads, a township outside Cape Town. The third section of the book briefly focuses on the roles of international donors. The final section consists of two chapters that poignantly illustrate the lives of children who are going it alone. Molatela is a 17-year-old girl who lost both her parents to AIDS in one week in July, 1999. She cares for her four brothers, including the youngest who is three years old and HIV-positive. Her courage is moving yet one feels deep sadness for the loss of her childhood, amongst other things.

> Having nursed her parents through terminal illness, she has become a substitute mother for her siblings. She is doing the best she can to wash, cook, and clean for a family of five, keep herself and her rebellious younger brothers in school, keep an HIV-positive three-year-old well, while dealing with her own grief at the loss of her parents. (p. 143)

The final chapter describes the tough lives of children of the street in Lusaka - those who are homeless and have no one to look after them. Their daily struggle to survive is described and the outlook for their future appears bleak. Overall, Guest's book provides insight into how poverty and grief overshadow the daily lives of children orphaned by AIDS in Africa.

Gow and Desmond's book has a more scholarly orientation than Guest's book and focuses on health, welfare and education issues as they relate to children and HIV/AIDS. The book provides a good overview of the socio-economic consequences of the epidemic on children in South Africa. In one chapter, Giese (2002) focused her discussion on the issue of health and well-being of children and asserted that the social and economic consequences of HIV/AIDS on children in affected households could lead to "reduced opportunity for growth and development creating a cycle of dependency, vulnerability, and abuse" (p. 60). The economic burden of HIV/AIDS can lead to food insecurity and malnutrition. Even when food is available, a child may have difficulty eating because of "a range of physical, emotional and psychosocial factors which play a role in appetite suppression" (p. 62). Orphaned children and children in affected households may have stunted growth and they are likely to be sicker than other children because of the environment in which they live. Besides not being able to afford to go to school, these children risk being abandoned. According to the 1999 annual report of the South African National Council for Child and Family Welfare, there was a 67% increase in the number of children abandoned over a 3-year period. Giese also indicated that children in affected households have to deal with "the double burden of prejudice related to HIV and prejudice related to poverty" (p. 62).

Two participants, Sizakele and Besta, brought up the subject of child-headed households within their community. Both had been moved by the plight of children who were left to fend for themselves after their parents died. And both tried to help out as much as they could by visiting these households and giving them food now and again. Sizakele recalled one household she had helped where a 15 year old boy was taking care of several siblings on his own:

> It is so painful...but there is nothing you can do. We do whatever possible which we can do to help, like I used to invite them for lunch...I gave R200 to this boy. Now since I am not receiving money, I don't know...I haven't said anything to him but I must call him and tell him I can't help.

When asked if this made her feel guilty, she said:

> I am not feeling guilty...because I just committed myself out of love. I felt like, okay, we can share this money...I gave him R100 for transport to school. Whenever I have some money, I will buy them polony so that they will be able to make some lunch for school. But it is so hard when it comes to money...Some people will say you are spoiling the child by

> giving him money. I said, 'How can you expect the children to go to school?' Anyway, this is what I did it for.

I asked Sizakele if people in the community were sometimes unsympathetic to child-headed households, and she remarked:

> Ja. I think it is because he is a boy and people have fears of giving children money because they will end up using it wrongly – the issue of drugs. They feel that maybe it might just make him do other things. To me, it doesn't matter as long as I have given up something with the hope of making a difference. So far he hasn't embarrassed me. Every time he is at home, you will find the house nice and the children are bathed. Ja...it is so hard. And I am thinking that…we are heading into the second week that I haven't given him anything…I am pretty sure he is taking no advantage.

Phumzile's mother and stepfather died when she was 15 years old and she was left to care for her younger sister. No-one in her extended family offered to help her. Out of desperation, she said: "I used my body just to survive…I would sleep with someone even if I didn't love that someone so long as he would give me money."

South Africa has seen a rise in the number of child-headed households and although this phenomenon has received a good deal of attention in the media, we still do not know much about the problem nor do we have reliable statistics on the number of children living in child-headed households. What is clear though is that child-headed households are extremely vulnerable. Giese (2002) indicated that these children are living on the margins of society, deprived of educational opportunities and recipients of few health and welfare services. In terms of the psychological impact, they have experienced the trauma of watching a parent die and they have to worry about who will care for them after the parent's death. Children in affected households also risk being sexually abused because they have no-one to care for them, though not much is known about this problem (Bray, 2003). Giese (2002) commented:

> For children living in HIV-infected households, children orphaned by HIV/AIDS and children who are HIV-positive, their basic rights to food, housing and healthcare are violated to the extent that their survival is threatened. (p. 74)

Mental Health of Children Bereaved by AIDS

While participants commented on the economic hardship of caring for children affected by HIV/AIDS, scant mention was made about concerns for the children's emotional well-being. There were a few exceptions, though. Azon mentioned how his pregnant daughter lost her husband and her mother back to back and he had been so worried about her. He said: "Sometimes I couldn't sleep when I thought about my daughter. I was worried about my girls." He continued to worry about them and was not happy with them living with his aunt far away from him. He said: "I give the aunt money for everything. When I went to the farm, my daughter said that her aunt is doing wrong things...they don't like living with her. I want them to live with me." Sadly, that never happened because Azon died a few months after our interviews.

Ragani was also very much in tune with the emotional needs of her nieces. She had been very concerned about what effect the loss of their father, then the mother, and then their little sister would have on them, so she took the girls to see a clinical psychologist. She said:

> I had to after the little one died...I was not going to let the children go through that – the process of depression, anger, the frustration all the time. You could see what was happening to them. They were always angry. At home, they were fighting with each other and you couldn't have a decent conversation with anybody.

She commented that when her brother was dying in the hospital, "everybody was so caught up in their own life – no-one really paid any attention to the kids, you know." At the time, the girls were fourteen, ten, seven and one year old. She was happy that she had eventually sought out counseling for them and remarked that they:

> ...lead a very well-balanced life. They're normal children. Their schooling has not been affected. They're fine. They're okay...I have learnt that children bounce back very quickly. They are able to deal with grief and they come around and they're fine.

Other participants viewed the challenge of meeting the child's basic needs as more urgent, perhaps because their economic circumstances were direr than Ragani's. We see the same trend in the professional literature. Researchers have failed to adequately explore the impact of AIDS-related illness or death on children's psycho-social well-being (Foster & Williamson, 2000). In fact, Wild (2001) conducted a review of the available literature on psycho-social adjustment of children orphaned by AIDS, but she was unable to locate many studies on this important issue. In her review, she incorporated some of the general literature on the impact of AIDS on children, but the main focus of her article was providing a synthesis of (only) eight research studies that had been conducted to date (seven in the US and only one in Africa). She reported: "At present, knowledge about the psychosocial adjustment of AIDS orphans is based on an intermingling of sound data, less reliable data and clinical observation..." (Wild, 2001, p. 8).

Drawing from a number of different sources (Wild, 2001; Loening-Voysey, 2002; Landman, 2002; Bray, 2003; Kaseke & Gumbo, 2001; Foster, 2000; Giese, 2002; Nyambedha, Wandibba, & Aagaard-Hansen, 2003; Young & Ansell, 2003), I have outlined in Table 8.1 common stressors facing children orphaned by AIDS that may cause psychosocial adjustment difficulties. It is essential that we learn more about the experiences of these children. Studies are needed to assess the prevalence of these stressors as well as their contribution to children's overall well-being. As Wild stated, "we do not yet have a definitive answer to the question of whether losing a parent to AIDS places children at increased risk for psychosocial adjustment difficulties" (p. 16). Bray (2003) supported this assertion and added that "it is clearly inadequate to simply assume a direct relationship between the parents' AIDS-related illness or death and the psychosocial health of children" (p. 46). It will be worthwhile, as Wild suggested, for research to identify factors that may mediate the relationship between AIDS-related deaths and children's psycho-social well-being. On a macro level, researchers need to be cautious about making alarming negative predictions about the impact on societies of AIDS-related orphanhood without sufficient empirical data (Bray, 2003).

Richter (2004a, p. 444) asserted that there is "consistent and ubiquitous" evidence of a positive correlation between socioeconomic status and children's psychological adjustment. Bray noted that since most children orphaned by AIDS in South Africa live in poor communities and parental illness and death are likely to worsen economic conditions in the household, a key question is "whether the presence of certain securities (such as shelter, a consistent care-giver, friendships and/or an income source) make a critical difference to the impact of parental death on children" (p. 46). To date, far too little emphasis has been placed on the psychological needs of children living in extreme poverty. Richter (2004a) criticized a prevailing attitude that these children have "primarily material rather than psychological needs, as if Maslow's (1970) hierarchy prescribed a strict order of need and experience such that a person cannot feel shy, hopeful, or humiliated when they are hungry and cold" (p. 446). Richter (2004b) predicted that besides poverty, the other main determinants of poor psychosocial adjustment for children impacted by HIV/AIDS are likely to be "loss, separation and bereavement" and "cruel and impersonal child care" (pp. 23-24). She added:

> At this stage its unclear how many children are exposed to unmitigated poverty, multiple loss and bereavement, and/or cruel and impersonal care. Of those children who are exposed to these conditions, it is not known what proportion will succumb to the effects of the associated stresses and begin to show disturbed behaviour or diminished capacity. (p. 24)

A review of abstracts of posters submitted to the recent XV international AIDS Conference that was held in Bangkok in July, 2004 provides disappointingly little evidence of research currently being conducted on the psychosocial health of children in affected households and children orphaned by AIDS. One has to wonder why 10 years after Sherwen and Tross (1995, p. 93) suggested that we develop "a solid base of knowledge concerning...children living in families with maternally transmitted HIV infection", empirical research has been lacking in this area. It is encouraging though, that since 2002 a regional technical psychosocial support resource network has been in existence. Called the Regional Psychosocial Support Initiative (REPSSI), this NGO offers technical support to more than 50 NGOs in East and Southern Africa (including South Africa) to build these organizations' capacity to provide psychosocial support programming, with the view that these organizations will in turn enhance the capability of communities, families, and children themselves to provide psychosocial support to children impacted by HIV/AIDS (Germann, 2004a; Matsika, 2004).

To address the gap in research on psychosocial needs of children affected by the HIV/AIDS epidemic, Strydom and Raath (2005) recently conducted a qualitative study of HIV-infected adolescents (as well as infected parents) in the North-West Province of South Africa. It was evident that adolescents were coping with several main issues including their psychological response to their diagnosis and their parent's diagnosis, stigma and discrimination both within their families as well as the community, and changes in social functioning (e.g., school attendance, friendships, taking over household duties because the parents were too ill). A priority was coming to terms with their diagnosis, and adolescents expressed a need for acceptance and support from family, friends, and social workers in conjunction with physical care.

Table 8.1 Stressors facing children orphaned by AIDS

Physical stressors:

- Possibly being HIV-infected themselves and being in very poor health
- Physical strain of caring for ill parents
- Fatigue from having to work inside or outside the household
- Reduced access to resources (e.g., shelter, food, clothing, health care)
- Neglect by relatives

Psychological stressors:

- Watching the disturbing clinical course of the disease in parents and other loved ones
- Experiencing multiple losses (e.g. parents, siblings, uncles, neighbours)
- Being deprived of parental love, guidance and support
- Having to live with other relatives or community members
- Multiple changes of residence
- Reversal of parent-child roles (e.g. taking care of the sick parent)
- Not having anyone to share feelings with due to a "conspiracy of silence"

Social stressors:

- Being denied a childhood by having to take care of ill parents
- Assuming responsibility for heading the household
- Not being able to attend school in order to take care of siblings
- Dropping out of school because household is unable to afford school fees, transport, and uniforms
- Susceptible to becoming a victim of crime, violence, or sexual abuse
- May be taken advantage of in foster care placements (their grants may be used to support the whole family or they may be used as cheap labour)
- Rejection from others because their parents died of AIDS and possibly cut off from social support (also may be driven out of their home)
- Having few role models
- Relocation to other households thereby losing friends and neighbourhood networks

In terms of how children respond emotionally to the loss of one or both parents to AIDS, Wild (2001) suggested that they probably had elevated levels of "internalizing problems" (e.g., anxiety, depression) and "externalizing problems" (e.g., acting-out behaviours, conduct disorders). Wild reported that these children were likely to have better adjustment if they stayed in the same household as their siblings, had a stable environment, were loved and cared for by committed family members, and had adequate social support.

I was able to locate additional sources of information about children orphaned by AIDS beyond those referenced in Wild. Carol Levine's 1993 book titled *A Death in the Family: Orphans of the HIV Epidemic* is a collection of articles focusing on the problem from the perspectives of children themselves, extended family members as well as professionals. This book provides a somewhat brief, though informative overview of the issues facing all those involved in helping children who are orphaned by AIDS in the US. Some of the key points from this book that pertain to the bereavement process in these children are as follows:

- Children may hide their feelings or be unable to grieve openly.
- They may experience "survivor's guilt" considering a parent's death from AIDS to be their own fault.
- Adults often are unable or unwilling to communicate with children about their views regarding a parent's death.
- Families may be reluctant to seek counseling out of secrecy, shame and stigma.

A book chapter by Aronson (1996) and an article by Mendelsohn (1997) discussed the psychological impact of AIDS on bereaved children using a psychoanalytical framework. These case studies of children, one of whom were African, recognized the importance of helping children re-establish positive attachments and identifications with the deceased parent, allowing them to express their grief openly, and helping them make sense of their world.

Dillon and Brassard (1999) conducted a small-scale study of 20 adolescents who had lost a parent to AIDS and the main purpose was to investigate the role of social support in coping with their loss. An important finding was that adolescents who had a greater number of people providing them with information and emotional support were more likely to use more coping strategies (probably because they were given more knowledge about specific coping strategies) and they were more likely to acknowledge a parent's cause of death as AIDS. Half of the sample named a relative who they said had helped them the most to cope with their parent's death. Eleven of the 20 adolescents reported that they found comfort in talking with other adolescents about their grief. Dillon and Brassard developed a list of systemic ways to help adolescents who have lost a parent to AIDS and they include:

- Along with HIV/AIDS education, teaching about the grief process and the importance of providing social support through forums such as schools, parent-teacher associations, and university departments.
- Offering support groups in schools for adolescents before their parent's death as well as after the parent's death.
- School guidance counselors and school psychologists should be made available to help these adolescents cope with their grief as well as depression.
- Outreach and support should be provided about the importance of giving adolescents the chance to say good-bye to their parents before they die, as well as making arrangements for them to attend their parent's funeral if they wish.

Worries about the Future Welfare of Children

In the current study, 10 out of 18 participants were HIV-positive and had children. For 8 of the 10 participants, the HIV status of their children was not known. Two participants had lost babies to the virus and both these participants had given birth again; one baby was HIV-positive and the other baby had tested HIV-negative so far. Nomusa was caring for her four-year old daughter who was HIV-positive when she got pregnant with another man (her daughter's father was deceased). She could not explain how it happened. She responded: "I know I wasn't thinking straight." When I asked her if she had been worried if the baby would turn out to be HIV-positive, she replied: "No. I didn't worry that much because I didn't even think about it. I was hoping that I wouldn't get pregnant." About a year after Prudence and her fiancé lost their four-month old son, they discovered that Prudence was pregnant, despite using condoms. She said: "I do know that is proof that they are not 100% safe." She went to an HIV clinic and was given nevirapine and had a caesarian. Today, her son was 15 months old and had been tested at 6 months and was HIV-negative so far. He will be checked again in a few months to make sure that he is still HIV-negative.

Scant research exists about the experiences of HIV-positive women who desire to have a child. Phumzile, 19 years old and HIV-positive, desperately wanted to live a normal life and have a husband and children just like everybody else. She asked me whether I thought she stood a chance of one day having her own children and a husband and when I asked if it was important to her, she replied: "Ja. I would like to feel the sense of belonging to a family – to somebody else." However, she was acutely aware of the possibility that her child could be infected:

> I love children...except that since there's no cure for this killer disease. I'm not sure whether I will ever have my own...It's risky, it's risky. Really, I'm scared! It's risky...When I do that, I would have to be with the love of my life because, really, it's risky...I would have to be financially stable.

She acknowledged that she was not ready right now to have children. Because most of the AIDS-related bereavement literature has focused on gay men, we know little about the experiences of bereaved women who are HIV-positive and raising children. Nomusa remembered when she was told that her six month old daughter was also HIV-positive. She said:

> The person who was supposed to be the counselor told me that children who are born HIV only live until about six years old. Then when she (her daughter) was six years old, I was panicking, panicking – because I knew that when she was six years she could die. I nearly died myself because I was so scared.

For HIV-positive participants, a constant source of anxiety was who would take care of their children after they died. Delarise said that in her workshops with people who feel they may be HIV-positive, the number one issue that is raised is who will look after their children. She said that they also worried about missing the "milestones in their kid's lives or their families." Prudence who had already lost one child, acknowledged that she and her mother occasionally had conversations about what would happen to her 14 month old son if she died:

> Sometimes she (her mother) does not feel comfortable with me saying things...but I know that we have to talk about these things: what I would want to be done when I pass away; I want my son to be taken care of; and who I want to take care of him when I pass away.

Sizakele worried about her deceased siblings' children as well as her own:

> As for the children, I think the worst impact is on them because they are relying on us as parents for everything. Now if they wake up not knowing what to do and who to shout at for any help, it's a problem. Every time when I think about it, it gives me such a pain because I think that today it's those children. Tomorrow, my ones are going to be in the same position.

Azon and Sibusiso were the only male participants who had children. Sibusiso worried about the welfare of his youngest child who was less than one year old but he did not express concern over what would happen to his other four children if he died. However, Azon, together with the other female HIV-positive participants, worried deeply about this issue. It is interesting that most HIV-positive participants had not spoken with other family members about this issue or made any kind of arrangements with them. Zanele acknowledged that she did not have a fear of dying, but she worried about what would happen to her six children because her parents were "very old and they will be going soon." She was angry with her husband who had deserted her and her six children.

She said that she saw no future for herself - all she thought of was that some day she would die and she did not know who would take care of her children. Sizakele, too, expressed anger at her husband who she felt she could not rely on to care for her children in the event of her death. She said: "I'm like a person who has no husband. Yes, he is there, but he is useless..." For Prudence, she knew she could depend on her mother to raise her child, but she worried what would happen if her mother died. Even though her mother was still young (her late 40s), this caused her anxiety: "What if my Mom dies first and maybe I will die after her – what will happen to my son? I think about that a lot." She did not believe that her fiancé's family would be of much help as he was not close to any of them, plus his mother "is old now".

Reason for Living

What was certain was how important children were to participants - they were their main reason for living. Zanele said that nothing made her happy except seeing her children: "Laying and talking with the children." Nomzamo, who like Zanele, lived in desperate poverty, said that it was her four children who kept her going each day. Prudence expressed similar feelings about her son:

> I am very grateful. I always ask God...if he can at least give me a few years to raise my son, to see him grow up, to see him when he goes to school for the first time...that is what keeps me going. When I wake up in the morning, I want to make sure he is ok...When he is around, I laugh a lot...My son is a very naughty child (laughs)...He keeps me busy.

Sizakele was asked if she felt at times alone in this world, and she replied: "I don't. I expect that if I didn't have children, I would feel that way." Bathokho, who was very ill, was hanging on to life so that she could raise her 10 year old daughter. She said that ever since she lost her husband when her daughter was one year old, she told herself that she had to live for her daughter's sake.

Conclusion

A great deal of worldwide attention has focused on children orphaned by AIDS. Yet, it is hard to explain why so little research has been conducted on the physical and especially the emotional well-being of these children. We know little about the emotional experience of children who watch a parent or parents die of AIDS and how they deal with uncertainty, relocation or abandonment by extended family. In the South African context, most people infected with HIV/AIDS have children and this provides a constant source of anxiety for them as well as comfort and hope. Children provide a reason for living but at the same time the parents worry about who will care for their children once they are gone. The lack of discussion and planning on this issue amongst participants was disturbing. In the next chapter, we turn our attention to participants' thoughts and experiences with regard to the period leading up to their loved one's death.

CHAPTER 9

The Final Days

This chapter describes the experiences of participants in the last weeks or days before their loved one died. It begins with an analysis of the different levels of awareness that participants had that their loved one had AIDS and was dying. This is followed by their assessment of the nature of their relationship with the dead person. Participants also shared their feelings about the type of medical care their loved one received and their own role in caring for the person toward the end. The final section deals with preparation for the death and the funeral.

Awareness Contexts

Based on a ground-breaking study among dying people in a hospital setting, Glaser and Strauss (1965) developed a four point typology of awareness contexts about death. In other words, they described four distinctive ways in which a context of awareness about dying influences interaction and communication with dying people. The typology is based on a two-person interaction. In the *open awareness* context, both the dying person and family member know that the person is dying. In the *suspected awareness* context, a person suspects that he or she may have a prognosis that involves death but this suspicion is not verified by those around him or her. Glaser and Strauss's third designation, the *mutual pretense* context, is one in which one or both parties pretend that they do not know the person is dying. At the end of the spectrum is the *closed awareness* context in which the person is not aware of his or her impending death, although others may know. I have attempted to adapt this theory to provide a framework for understanding awareness about both HIV and dying among participants and the dying person and how it shaped communication. I have broadened the meaning of each context and Table 9.1 shows how I have adapted the theory of awareness for the purposes of the current study.

Table 9.1 Awareness contexts

Open: Both the dying person and the family member know that the person has AIDS and is dying.
Suspicion: One or both parties suspect the person has AIDS and is dying.
Pretence/denial: One or both parties pretend that they do not know the person has AIDS and is dying or are in psychological denial.
Closed: Knowledge of AIDS and dying is hidden from the dying person.

[adapted from Glaser & Strauss, 1965]

Open Awareness

In this awareness context, I propose that participants and the dying person both know that the person is dying and that he or she has AIDS. This type of awareness context was rarely experienced by participants. Only in Ragani's case was there open discussion between her and her brother that he was dying of AIDS. However, this exchange only occurred shortly before his death and some family members were only informed at the last moment. Ragani said:

> My mom didn't find out in fact until a day before he died. We didn't know how to tell her. The problem was that we had to tell her because...the doctor suggested that my sister-in-law has to go for the test and take the children with her...and she (sister-in-law) got her results just the day before my brother died, but by then, he had basically lost his mind. He didn't recognize his family...he was living his life back in his twenties...didn't remember he was married and had children and all of that, so he didn't even know his wife's status when he died. So, when she found out, it was time to tell my mum. She needed to know. She was devastated. She knew as a Mum, for some reason...she was losing her son. When she would visit him in the hospital, she would tell us, 'You know, he's not going to make it'. Mothers have that instinct, I suppose.

Suspicion

Most participants had suspected at some point that their loved one was ill with AIDS, though few realized that the person was dying. In almost every instance, the ill person denied that he or she had AIDS when asked. Several participants who were HIV-positive themselves gently approached the person and tried to get them to disclose, but without success. Sibusiso had witnessed his mother and aunt die of AIDS and he recognized the symptoms of AIDS when his brother got sick. But his brother refused to talk about it. Sibusiso said:

> I begged him to tell me what was bothering him. Even though I knew, I didn't want to say anything because I would have lost my friendship with him...It was very painful and frustrating...The feet were swollen, the legs were a different shape and he would sleep sitting at the table. That worried me a lot. Every time he coughed at night, I would wake up and see if he's ok. Sometimes at night when he went to the loo (our loos are outside the building), I would escort him. I would hear him growling. He couldn't walk anymore and I would pick him up. It was very painful and sad at the same time.

Some participants encouraged their loved one to get tested after detecting well known symptoms of HIV/AIDS such as wasting, diarrhea and night sweats. Sizekele who had already lost three siblings to AIDS tried to get another brother to get tested but he refused. This frustrated her greatly because "he was qualifying for the ARV - he was working for a company which provided them with medical aid...He had the means to afford the treatment." Sizakele experienced resistance from other relatives as well in terms of getting tested:

> I have got one cousin...he is in the hospital. He is just finished. He started to get sick in December last year, and I could see how much girls he had infected. He kept on saying he was suffering from piles and loss of appetite and I said, 'How come?' What was ironic was that this cousin was

> a teacher who was knowledgeable about HIV/AIDS, and in the past, he had actually encouraged family members to get tested.

Both Felicity and Mthoko had knowledge that their loved one had AIDS but the person refused to discuss it. Felicity's best friend refused to confide in her even though Felicity had found out from another source that the friend was HIV-positive. She said:

> There was no secret of hers that I didn't know except this trick HIV that she didn't want to talk about...It wasn't easy for me just to say, 'I know you are HIV-positive', though the signs was there...The symptoms...were very obvious now. So, one day I took a step and I went alone to her. I sat with her and I just ask what is going on inside of her. She said a lot of things. Her child is worrying her now. She just talked about the outside, than of addressing the real problem. I said it's very important to know your HIV status because when you're HIV-positive, we do something about it...But she didn't want to say a word about HIV...her feet were like swollen, her stomach was like a nine month pregnant woman...I think she understood that there was somebody who cares for her even if she doesn't want to talk about it. But at least there is somebody who shows that I love her. I think that was the best part. When she would see that I care and I still love her and she can trust me if she wants to but I couldn't force her."

After Mthoko's brother's baby was sick and was diagnosed with AIDS, his brother and his wife were tested and he later learnt that they were infected. His brother moved away from his family. "He didn't want to involve them in his story," said Mthoko. He went to live with the mother of his baby. The brother refused to tell Mthoko himself that he was HIV-positive: "He didn't want to talk about it."

Pretence/Denial

Some participants were hesitant to confront a loved one about their status or to talk to them about getting tested, so they put up appearances that they did not know the status of their loved one. Bathoko suspected that her sister was ill with AIDS but no-one in her family addressed the issue. She said:

> She was 28 or 29. She was a very strong person...This thing started when she fall pregnant. Something was going wrong. She was very weak...We were taking care of her but we were wearing protective things. She's got something that she is hiding...Three weeks after the child was born, she (Bathoko's sister) died. The child also died after four months...She was afraid to tell the truth....She didn't tell us. She kept it a secret from us. But she told her friends...If a person doesn't want to tell you exactly what it is, what can you do about it?

When her best friend died, Felicity said: "Nobody mentioned a word about HIV. The thing is when somebody does not talk about it, everyone is scared just to come up front and talk about it. Her family at the end of the day knew it was HIV." In the same vein, Besta observed:

> There are a few in the family who have symptoms but they still are not saying anything...It's very clear they are HIV...I don't actually blame them. But I just say to myself that maybe it's time because all diseases kill, although this one is worse. But I just don't blame anyone as I just think it's time. It's life.

Tuli and her mother did not talk about her sister dying. "We knew she was going to die," Tuli remarked. "Sometimes when things are painful, you don't want to talk about it, so...there was an understanding." What occurred more frequently was denial that a loved one was dying of AIDS. Even though Nomusa had HIV herself and had already lost two sisters to AIDS, she had a tough time acknowledging that her brother was infected. She said: "At this moment, I am worried about my brother. Initially, he complained of stomach pains. After some time, they found acid and they drained it out. And even after it had been drained out, the pain continued." When asked if she thought he could be HIV-positive, she replied: "I don't know...His wife is fine...The child is looking fine...I really thought he is maybe hiding something from us...maybe it's something else."

When Nomusa found out her daughter was HIV-positive, her husband refused to accept the results. She tearfully recalled: "The worst part of it is that I spoke to the father who just denied everything...And then, I thought, if it is this much difficult for him to understand, how is my family going to take it?" The baby's father disappeared shortly afterward. He got married in a year and he died a few years before his daughter did. Similarly, when Prudence found out that her infant son was HIV-positive, her fiancé (the father of the child) had a difficult time accepting it. She said: "At first, he was denying everything. He was in a state of denial. He said: 'No, but my son is healthy and I know you took a test before.'"

Doris, an educated woman, had not recognized that her brother had AIDS even though she had lost her husband to the disease. She claimed to be very close to her brother and expressed shock upon learning that he had died of AIDS, even though he had been very ill and "in and out of the hospital." She said: "I found out late...People are not educated about AIDS. If I had known, I would have helped him, visited him, counseling him – to give him hope, medicine. I would have encouraged his wife to be supportive."

Azon, who had been sick for some time and had tested HIV-positive some years back, still questioned his own status. What was interesting was when I asked him if he had lost anyone recently, he said a 25 year old cousin died four months ago, and when I asked the cause of death, he said: "I don't know, maybe AIDS." So Azon clearly recognized the symptoms of AIDS in other people - as he had them as well, but it was hard for him to accept that he too had AIDS. He did not know the status of his two daughters and one had just given birth. When asked whether he thought they should get tested seeing that he was HIV-positive and his wife had died of AIDS, he replied: "I am not too sure." Azon still clung to the belief that he could be HIV-negative and said: "I want to go back and get tested."

Just before her brother disclosed to her, Ragani said: "At that point, he could barely walk...He was really so weak...When he died, he weighed 38 kilograms." She acknowledged that she had been in denial: "I just kept brushing it aside and said, 'No, it can't be! Not my brother!'"

Tuli claimed that she and her mother had no idea that her sister could be infected:

> We didn't know she was HIV-positive because she was pregnant and she had a baby with a caesarian section. But the thing is that she had problems and the illness didn't get cured. She was in and out of hospital and she wasn't disclosing anything...she wasn't saying anything. So we just thought the doctors had made mistakes, so we were telling her to sue the doctors. Most of the time, she spent in the hospital and it was getting worse day by day. Nobody suspected HIV. In fact, with HIV, if it strikes in the home, you don't think it's HIV because you always have the feeling that it's for people who don't behave well, and I know my sister – she was a one man woman....So I never associated her sickness with HIV.

Closed Awareness

Nomusa refused to tell her nine year old daughter that she had AIDS and the same was the case for Ragani and her six year old niece she cared for. Both participants wanted the girls to live as normal a life as possible and they felt that telling them they had AIDS would be too disruptive. They did not discuss the issue of dying either. However, Ragani sensed that her niece knew that death was near:

> The little one didn't know what was wrong with her. Just two weeks before she died, we were lying together in bed. She looks at me and asks, 'Ragani, am I going to die?' I was unprepared but we did know a question like that might come up some day. So I told her, 'We all have to die, but now is not your time.' It was so strange she would ask this question two weeks before she died, as though she knew something was happening to her!

Relationship with the Deceased

As noted in Chapter Three, there are a number of variables that influence the duration and intensity of the bereavement process. Examples include the socio-cultural context of the mourner and whether or not the death was expected. Another variable is the nature and quality of relationship with the deceased. As Dane and Miller (1992) noted, the intensity of the grief reaction is directly related to the degree of closeness between the person and the deceased. Although there were some exceptions (e.g., Tuli, Azon, Doris), most participants drew strength from their close bonds with the deceased. For example, Sibusiso talked about how his brother was someone he had looked up to. He remarked:

> Hey, I miss him! He was very jovial, playful and very bold. He was a mentor to all of us... Whenever I mention his name, you will hear others repeat his jokes...We have three of his photographs in the house...We miss him very much, we miss his jokes, his advice. He inspired me to come out (to get tested for HIV)...I have great memories of us when we were in primary school.

Nomusa's face brightened when she spoke about her daughter, Zama, and how she had enriched her life in many ways despite the burden of AIDS:

> She was very clever, because even at school when she was sick, her teachers would send her homework, and she was one of the top students. And then she couldn't go to school anymore, just because of the fact that she had been at the hospital for a long time. She ended up being some sort of messenger in the hospital. When she was feeling okay, they would send her something to be taken to X-rays, wherever....And she was an outspoken child...She would sit in the superintendent's office and just sit with her. And in November 2001, she was nine years old and she went around the hospital with invitations for her birthday; it was like a wedding. There were a lot of people on the ward and I could see that they truly loved her. That's just how she was. (Nomusa showed me her photo). She

> had a lot of fun on this day. She had a most wonderful day...She ended up making a lot of friends for me. I have people who I now know who are very good friends of mine –who were friends of hers.

Even Tuli found something positive to remember about the type of relationship she had with her sister. Though they had not been very close, she prided herself on the fact that "she respected me because I am an older sister." Tuli had attempted to be a role model for her sister and had no regrets about her relationship with her sister. But she was disappointed that her sister had not told her she had HIV: "If she had told me, as an older sister I would have done my research and helped..."

What is interesting is that at least one half of the participants talked about their relationship with the deceased not only in terms of the emotional bond they had with them but also how helpful the deceased was in giving them money, shelter or helping them around the house. When their loved one died, participants had to adapt on an emotional level to their loss and also address the void left in the household with daily subsistence needs. As I described in Chapter Seven, poverty and the struggle to survive on a daily basis was a major focus of participants. There are several ways one can define a "central" relationship between the person and the deceased, according to Dane and Miller (1992). It can refer to the love between the person and the deceased and the fact that the deceased person's presence was so profound that life without them seems unimaginable. The deceased may also be considered central if they were a vital source of daily support, not only emotionally but physically as well (e.g., daily caregiving).

Quality of Health Care

As the person grieves, there is a tendency for events of the past to be recycled in the present (Dane & Miller, 1992). This can include thoughts about unresolved issues in the relationship or doubts about whether the person did everything possible medically for the deceased. Many of the bereaved in South Africa are confronted with the reality that their loved ones died because they did not have access to ARV treatment that is relatively easy to obtain by infected people in developed countries. According to the latest UNAIDS report on the epidemic, of the approximately 25-28 million people living with HIV/AIDS in Sub-Saharan Africa, only a paltry 150,000 people had access to ARV treatment as of June 2004 (UNAIDS, 2004). Watt and Burnouf (2002) chastised the medical establishment for being self-congratulatory about advances in medical treatment for AIDS when so many millions of people worldwide cannot access these treatments:

> "Living with AIDS" is the politically correct euphemism. Dying with potentially manageable HIV infection is the horrible reality. Can there be a more shameful medical emergency than 30 million patients' urgently requiring life-prolonging therapy and not getting it? (p. 710)

It is interesting that not one participant voiced any bitterness that his or her loved one had died before ARVs became available in South Africa which could have extended their lives. This is contrary to anecdotal accounts among the bereaved in the US (Demmer, 2001a) who felt cheated that their loved ones did not live long enough to benefit from ARVs which became available in 1996. Only Nomusa commented on the issue of ARVs but her perspective was slightly different. She voiced relief that her deceased daughter was not around to be denied access to ARVs while others had access to them: "Thank God she passed away before she could get help from ARVs. I think that would have been the most terrible, painful thing - that help is here but she cannot get it." Incidentally, Nomusa's other five year old daughter was currently receiving ARV treatment.

Because it was only at the last moment that most participants realized that their loved one had AIDS and/or was critically ill, only a few of them were actually involved in caring for the person or had experience with the type of medical treatment they had received. So, most participants did not have much to say about the medical care for their loved one. There were a few exceptions however, such as Nomusa, Prudence and Ragani, who had lost children to AIDS. Nomusa was grateful for the care the hospital staff had given her daughter. She commented: "I know that she got the best care. She ended up being a well known person in the hospital. I would see everything they were doing for her. I was 100 percent satisfied. They did everything they could." Ragani and Prudence had mixed feelings, on the other hand. This is what Ragani said:

> I had a bit of a problem in terms of race because Shanni was the only Indian child on the ward...When I went there, I had to sign my name in a book...You were supposed to be seen as per when you signed in the book. I noticed several times I waited much longer than the others who had signed in after me. It was a racial thing. If you were Indian, then you wait. One day, I just lost my temper. Yes, I have had bad experiences!

But Ragani was very happy with her niece's primary doctor:

> This particular doctor...he had the most beautiful blue eyes and Shanni looked forward to seeing her blue-eyed doctor. He was very good to her. He would laugh and joke with her and make her comfortable first. He shared a very good relationship with Shanni. He was caring.

Prudence too noted how the quality of treatment varied between institutions and medical professionals:

> You know, everywhere, in every different place, every different institutions like hospitals, you'll find different treatment – especially in public and private hospitals – it is very different. The staff in the baby's ward...was very nice. But here are a few people that they didn't want to be affected by our children...Some nurses can't even touch a baby...Some were nice and understanding. Some were awful."

When asked how she would rate her experience with medical personnel during the four months her baby lived, she replied: "I can say 70 percent okay. People are different. Some doctors are...more comforting than nurses. They are very understanding and they are very caring, if you compare them to nurses." But she remembered one nurse who had been comforting: "There was always a nurse who always came to me and said I am praying with you and your son will be fine...She always had a positive attitude and positive stories to tell. She was very nice." Sibusiso also had good things to say about the medical personnel who treated his brother:

> The staff was very supportive...The medical doctors were so fond of him. The doctors gave me plenty of time with Patrick in the hospital. They were very kind. It depends on how you approach them, even if they have strict visiting hours.

Several participants thought that the medical staff did the best they could, considering their loved one was in the "last stage", as Monica put it. On the other hand, some participants had quite negative experiences. Felicity commented that she had heard "that when people are HIV-positive, they just ignore them." For Azon, the hospital that had treated his wife was "not a good one at all. Everyone who goes there doesn't come back." Zanele complained:

> They treat patients very bad. Sometimes you go to the hospital and are very sick and you're sitting there and they tell you to just go home. They just don't care....Part of the reason is because some think you're a burden.

Since the mid-1980s, there has been a steady stream of research studies, most of them conducted in the US, examining attitudes of health care workers toward people with HIV/AIDS. Several comprehensive reviews of the literature on this topic (Horsman & Sheeran, 1995; Bennett, Miller, & Ross, 1995; Valimaki, Suominen, & Peate, 1998) have shown that negative attitudes by health care workers are prevalent. The main concerns that health care workers usually have are discomfort working with stigmatized groups (such as gay men or drug users), fears of contagion, attributions of blame, and the stress of working with patients who were terminally ill. Although the AIDS landscape has changed dramatically in the last 10 years within developed countries, health care workers continue to be vulnerable to stress and burnout, and this together with negative attitudes, can compromise patient care (Demmer, 2004b). Insofar as Africa is concerned, we have only a small amount of literature on this topic but hopefully it will expand in the future.

A couple of local studies, selected at random, indicate that some health care workers definitely display discriminatory attitudes toward patients with HIV/AIDS. Furthermore, many workers are overwhelmed and feel unprepared to handle the challenges associated with HIV/AIDS care (Adelekan & Joyalemi, 1995; Strydom, 2002; Moore, 2001; Fransman, McCulloch, Lavies, & Hussey, 2000; Smit, 2005).

There is no doubt that there are many dedicated medical professionals in South Africa who care for patients with HIV/AIDS, however the health care system is ill equipped to handle the enormity of the HIV/AIDS crisis. Tremendous burdens are being placed on the public health care system (Walker, Reid and Cornell, 2004). Some public hospitals have had to turn patients away, and physicians have been forced to make difficult decisions about limiting treatment and deciding who to save (Henderson, 2000b; Walker, Reid & Cornell, 2004). This desperate situation was summed up by Karen Michael, an AIDS researcher in Durban: "We can't afford to spend money on people who are going to die" (Henderson, 2000b, p. 20).

There are still huge disparities in health care after Apartheid and movement toward a national health service has been slow (Benatar, 2004). Walker, Reid and Cornell (2004, p. 73) commented that "health services are most available to the people who need them least. Those who need health care the most have inadequate access to it."

AIDS has exacted a devastating toll among South African health workers as well. Based on a nation-wide representative sample of 721 health workers employed in public and private health facilities in four provinces, Shisana, Hall, Maluleke, Chauveau, and Schwabe (2004) reported that approximately 15.7% were living with HIV/AIDS in 2002. Professional health workers had a HIV prevalence of 13.7% and non-professional health workers had a prevalence of 20.3%. Rehle and Shisana (2003) predicted a bleak future for the health care system in South Africa as a result of the AIDS epidemic:

> ...it is expected that that the number of people seeking care is likely to increase substantially, "crowding out" those who suffer from non-AIDS related illnesses. As more AIDS patients need care, staff are likely to experience "burnout", low morale, and increased absenteeism. The health care workers, as part of the community, might also become infected and

> develop HIV/AIDS-related illness, which will render them unable to provide health care to those who fall victim to the disease. This may result in a non-functional health care system... (p. 7)

Palliative Care

Felicity was the only participant who reported that her loved one received care in a hospice. All of the other participants indicated that their loved ones died in a hospital, with the exception of Ragani whose niece died at home. Ragani was critical of the hospital's inability to provide palliative care to her six year old niece:

> After we lost my brother, we realized that as much as a hospital keeps them alive, a hospital does not give them the love they get at home which is what they need. At the end of the day, they are going to die. If you leave them in the hospital, they are just going to waste away there...

The issue of how to provide adequate care for the dying in Sub-Saharan Africa has received much attention in recent years, largely as a result of the HIV/AIDS epidemic and the unavailability until recently of effective, life prolonging treatment. However, there is a dearth of research studies on palliative care in Sub-Saharan Africa (Harding & Higginson, 2005). In one report, Uys (2003) observed during hospital visits "gross undermanagement of pain observed from patients' case notes and by observing patients in pain" (p. 276). A study by Henley (2002) at Red Cross War Memorial Children's Hospital in Cape Town revealed alarming inadequacies in the provision of terminal care to children with AIDS. Henley reported that more than one half of these children experienced pain and distress in their last 48 hours "that was not treated, was under-treated or was treated too late" (p. 51). There were significant problems with medical providers adhering to documented comfort care plans that focused on comfort and pain relief rather than providing life-saving medical treatment.

There is widespread agreement that we need more clearly defined national policies and strategies and also more funding to support palliative care for people with AIDS in Africa (Jagwe, 2002; Kikule, 2003; Sepulveda et al., 2003; Uys, 2003; Norval, 2004).

In a report in the British Medical Journal, the chief executive of St Luke's Hospice in Cape Town was quoted as saying that only 250,000 of the 5 million or so people with HIV/AIDS in South Africa who require palliative care (including home support and pain relief) actually receive it (Carlisle, 2003). A recent study of 103 adult patients with advanced stage AIDS in South Africa revealed that pain was the most prevalent symptom and it was also the worst overall symptom (Norval, 2004). The most prevalent pain was lower limb pain (66%), followed by mouth pain (50.5%), headache (42.3%), throat pain (39.8%) and chest pain (17.5%). Furthermore, females reported significantly more pain than males.

Because ARV treatment is currently out of reach for most South Africans living with HIV/AIDS, providing palliative care is sometimes the only option, but this service is grossly under-funded by the government (Uys, 2003). Leana Uys, a nursing professor at the University of KwaZulu-Natal, has written several publications describing an integrated community-based home care (ICHC) project for terminally ill AIDS patients at seven sites throughout South Africa (Uys & Hensher, 2002; Uys, 2002; Uys, 2003). This model of care consists of collaboration between a home care team, hospice, clinics and hospitals (Uys, 2003). Community caregivers are women from local communities who receive three months training and are then supervised by registered nurses (Giarelli & Jacobs, 2001). The community caregivers "provide care, information, supervision, and support to the PWA, their families, and the microcommunity in which they live" (Uys, 2003, p. 273). This model of care shows much promise as a cost-effective way to address the palliative care needs of dying AIDS patients (Uys & Hensher, 2002). As De Guzman (2001) noted, home-based care and community-base care are models of care that "are well suited to settings where resources are scarce and health care facilities and personnel are limited" (p. 669).

But there are enormous challenges that community caregivers have to confront, one of them being providing palliative care in the midst of abject poverty (Uys, 2003). In an interview with Giarelli and Jacobs (2001), Uys reported:

> Caring for a person with full-blown AIDS is not easy. You may be living in a little house with no running water, and no effusion facilities. The

> washing gets done in the river, which is 300 meters down the hill and up the hill again, and you have a patient with diarrhea, so you are washing all the time. You're also the only person looking after this patient and helping them out of bed and onto toilets, and so on. It's very difficult work. (p. 60)

Besta described her experience as a community caregiver:

> It's so sad because most of the houses that we visit we find that the family has isolated him or her – they are not doing anything…They show they are not accepting the situation and the caregiver has to educate the family but still they won't understand especially when they have been told the person has AIDS…It's so sad because in some families they just leave the loved one like that…As caregivers, they've got a lot of things to do…They have to cook porridge or go home, pack food, and come back.

Besta estimated that she cared for about eight people a week. "It's really hard to do home visits," she said, "because some people don't like us coming in…They say, 'No, our child is not suffering from HIV/AIDS.'"

Family Caregiving Experience

Just as De Guzman (2001) reported, it was mostly women in the current study who bore the burden of caregiving. The dominant feeling among participants was how difficult it was for them to take care of their loved ones with so few resources. Yet, they did so without hesitation. De Guzman noted that as the AIDS crisis worsens, "the collective ability of family and communities to cope may become severely strained and the traditional caring role may be abandoned, especially without increased external support" (p. 671)

Few participants had any regrets about their role or doubted that they could have done more under the circumstances. Nomusa, whose daughter finally succumbed to AIDS at the age of nine years, commented: "I know I loved her and think that maybe it was enough - that I did everything every way I could." Occasionally she wondered whether she could have done more "but then I console myself and say I didn't have much."

The strain of not being able to do much while watching a loved one deteriorate was heart wrenching. Ragani described caring for her sister-in-law:

> My sister-in-law even was not put in the hospital...We nursed her and took care of her at home until she died. She died at home...We worked out a time table. My Mum would do the day shift and I would do the night shift...I would never want anyone to go through something like this and I said, dying is one thing but the suffering was bad for all three...What he (brother) may have suffered at midnight or the times when we were not there, we don't know anything. But, my sister-in-law, we were there with her, right till the very end. Five days before she died, she had a stroke, she couldn't talk. It was terrible...Our family doctor would come and visit her and give her painkillers etc. He used to always tell us to give her painkillers and keep her comfortable – nothing else. No medication will help her anymore...

Bathoko who was sick herself at the time, spoke about caring for her sister:

> I think we gave her everything that we could. Sometimes, she couldn't eat – it's a big problem. Sometimes you know she is hungry, but she can't eat, then you have to sit down and talk her to at least have some porridge...You can't do anything. You just keep looking at her if she's still alive...At night, you must wake up and see if she's still breathing. I couldn't think of anything but her and how I can help her...She was a very strong person and to see her lying all day because she had the AIDS virus and she hasn't eaten anything...It was very hard.

Mthoko painfully recalled the day when his brother could no longer see: "It was then that I realize that this is a terrible disease. It is only now that some of the people can live a little more if they look after themselves – but then it was different."

Besta was touched that it was she that her nephew had chosen to help him in his dying days. She was the first person he told about his HIV status; he knew that she would take care of him, that she was responsible, and that she loved him. She said: "It was so sad. I'm like a mother to him…The hardest part was when I bathed him. I was hurting him as his whole body was so soft."

Like other participants, Sizakele had barely enough money to feed herself and her family, yet this did not stop her from taking her sister-in-law into her home and caring for her for two months until she died:

> I was the only one taking care of her. From the time she came, I was all by myself. Sometimes it was even difficult to negotiate with other neighbours that did the home- based care, to help me bathing her, taking her to the loo…Sometimes when I want to go somewhere, even to buy some medication, some groceries, I had to leave her with somebody…I must feed her, I must bath her, I must wipe her when she's in the toilet. I must do everything...And I was very strong for her…until the last, last moment…I feel very proud and responsible…I managed to make it happen. I felt great and I felt that I did the best that I can.

Some participants, like Nkosi and Monica, reported that they had initially been worried that they could become infected as they cared for their loved ones. After both tested positive later, they acknowledged that they probably contracted the virus through sex and not from caregiving tasks. But Monica still worried that her best friend's mother could be infected as a result of caring for her daughter: "She had no gloves on and had blood on her…"

Few studies have examined the experiences of families caring for a loved one who is dying from AIDS. Cody (1995) studied the experience of 10 families who were living with someone who was dying of AIDS. Four major processes were identified: adjusting to the push and pull of unwelcome and welcome changes, bearing witness to suffering and being there for the loved one, facing possibilities for change in the midst of confusion, and focusing on being close with others and living for today.

Not Anticipating the Death

As a result of being in the dark about their loved one dying, several participants had limited involvement in caregiving tasks and some were disappointed that they did not have the opportunity to be there for the person at the end. A frequent comment was that their loved one died 'suddenly'. As Felicity noted: "It was very quick." Azon was scheduled to take his daughters to see their mother on a Sunday, but a few days before, his daughter called to inform him that she his ex-wife had died. He reported that she had only been sick for two weeks. In some instances, the person worked up until a week or so before he or she died. Nkosi said that he knew that his mother would die "but I did not expect so soon…I cried when I started thinking about it – how am I going to live?" Mthoko lamented that he did not know that the time with his brother would be cut so short. He maintained that if he had known, he would have spent more time with him. He commented:

> I ask myself, 'Did my brother deserve this?' But I realize that there are things that you cannot judge them as you see them…I feel for my brother because he had goals and never reached them. Worst part is that he lost a child…

One of the hardest things for Felicity was her friend's denial that she had AIDS and her refusal to talk about it right to the end:

> I found it difficult for me to push her in explaining because I saw that she didn't want to talk. The more you go to the HIV story, she would be upset, very much upset. You would hear in her voice even though her voice was gone, but she would be like trying to stop you from talking about that. It was hard but I wanted to get through her but I couldn't…I

> wasn't crying for her of AIDS...but...of denying the whole thing and knowing that she can't get help...support...I don't think I can regret anything because I have done my part.

Koop and Strang (1997) reported that a recurring theme in the literature on bereavement outcomes of families of cancer patients was "the need for open awareness of the impending death and for careful and thoughtful planning of the location and circumstances of the death" (p. 46). We need to investigate whether there is a correlation between open awareness and bereavement outcome among families of AIDS patients in the South African context.

Foreboding

While some participants did not anticipate their loved one's death, a few others had a feeling that their loved one was about to die soon. Sibusiso remembered telling his brother's girlfriend that his brother "would be very, very lucky to survive the year...seeing the way he was and seeing my aunts dying the same way..." Prudence recalled:

> I had a feeling that I am going to lose my son. Four days before he passed away, he was in the ICU. When I entered into the ward, my son looked like he was fast asleep. While I was there – it is the very moment that I will never forget in my life – I stand beside his bed and he started gasping. I cried and ran out and when I came back, he was gasping blood. Oh, I cried!! I could not forget about that day. I had a feeling that my son was passing. I ask the Lord, 'Why, why, do I have to see this?' This should have happened while I was not there! I tried calling my Mom. I could not find her. I was crazy. Even today, I ask myself, 'Why I have to see that because it could have happened anytime when I am at home.'

She added: "The very same day he passed away, I was very tired. I could not do anything. I could not bathe myself...I got this bad feeling that something was wrong but I did not know what it was."

For both her brother and niece, Ragani had a warning that death was near. With regard to her brother, she recalled entering the hospital room: "It was the first time ever I saw him with an oxygen mask and his breathing was funny. And that is when the realization hit me, 'You know what, this guy is not gonna make it – he's going to die.'" She did not talk to anyone about this feeling because she felt she had to be strong for her family. "I've got to put on this brave front and say, 'No, he's going to be alright.'" He died three days later. Ragani said that her brother knew he was dying: "Some of the things he said to me didn't make sense like, 'Please, I need you to take care of my children. I need you to make sure they get a good education...Make sure they marry a good guy.'"

It was difficult to gauge the extent of anticipatory grief among those participants who were expecting their loved one to die soon. Rosen (1998) suggested that anticipatory grief enables the person to involve the dying patient in tying up loose ends, ironing out personal conflicts and saying goodbye. The process of anticipatory grief appeared to be truncated among most participants, either because they did not expect to lose their loved one or they found out at the last moment that he or she was dying.

There has been limited research on the psychological impact of AIDS-related bereavement on families (Stajduhar, 1997; Robinson, 2001). A few qualitative studies have explored the experiences of family members as they care for a loved one dying of AIDS. Brown & Powell-Cope (1993) conducted in-depth interviews with 53 family caregivers of persons with AIDS. The term "family caregiver" was defined broadly to include biological family members as well as partners, friends, and others who were performing surrogate family functions. The final sample of family caregivers was composed primarily of partners and friends while parents and siblings only made up 17% of the sample. The person with AIDS was usually a gay man and the study was conducted in an area in the US. The themes that were identified dealt primarily with loss and shifting one's sense of time to focus on living in the moment. This study provided a detailed and poignant examination of anticipatory grief among family caregivers of people dying of AIDS. Participants reported multiple losses as they confronted the eventual death of their loved one to AIDS. The most painful and consuming aspect of living with loss was preparing for the death of their loved one, and other losses included dreams for the future, their personal freedom and their previous lifestyles. Loss pervaded all aspects of their lives including personal relationships, work, and leisure time. The researchers of this study concluded that "intense bereavement" occurs during the caregiving period as well as after the death of the family member (Brown & Powell-Cope, 1993, p. 188).

In looking at studies on the predictors of bereavement outcome, Koop and Strang (1997, p. 40) suggested that open awareness or awareness of impending death may facilitate "health grieving". For those who had witnessed the ups and downs of caring for their loved one for a long time (such a Ragani and Nomusa), the primary focus was probably on keeping the person alive, rather than contemplating their death. It is possible that participants repressed their feelings because the prospect of a loved one's death was too difficult to accept.

Getting the News of the Death

The moment when their loved one died was etched in the memory of participants like Ragani and Zanele who were present at the time of death. Ragani explained:

> She died in September but I knew in June, having been through two before that…when her eating habits changed. On September 5th, she was really, really ill – I mean extremely ill…So I took her to our family doctor. He looked at her and said, 'I'll be very honest with you: Shanni is not going to make it." So I looked at him and asked him 'How long?' He said, 'Look, I am not God, but maybe two weeks.' So I said, 'Ok, fine' and walked out. But then I turned around and asked him, 'Are you sure?' He said, 'Just watch her tonight.' And I went home. The "watch her tonight' kept ringing in my head. I phoned the maternal grandmother (I did the right thing) and told her that Shanni was quite ill (She didn't know she had AIDS). I told her 'Shanni is quite ill, I don't know how long she will live. Please come and see her'. And we called our closest relatives during this

time...So the family came and visited her...And that night...it started at 4pm...she started bringing up blood...At midnight, her elder sister, my mum, my aunt and my cousin decided to stay up that night. At midnight...she was sending everybody to bed...She told Indira to go home, she told Shanta to go to bed because she had to go to university tomorrow. She told my mother to go to bed 'because you have to get up early tomorrow morning.' She was merrily sending everybody off to bed, so I jokingly said, 'What about me?' She said, 'No, you sit here with me.' But nobody left...Around 1am, she started fighting for her life...and at 2am it was as though she gave up the fight. She lay there comfortably...Eventually at 4am...she said, 'Carry me, please carry me.' I took her in my arms, sitting on the bed, and the next thing I know – it happened so fast – she's looking at me but not looking at me...I had never seen anyone die before...so I didn't know what was happening. So I asked my aunt who is an old lady, what was happening. She said, 'Just hold her close to you.' And I was holding her so close to me I could feel her heart beat – and I felt it stop...The last look - to this day I will never forget. She didn't know her HIV status because we wanted her to be a normal child. We didn't want her to get depressed like her mother...But the last look she gave me before she died –'What's happening to me?' She died, she stopped breathing. There was a little baby in my arms. I sat with her five or ten minutes. Then I lay her on the bed and then I walked away. I just walked away. I promise you, I did not touch her after that. I couldn't, I just couldn't. She and I had formed a bond – we were very close....On Mother's Day, she made me a card which said, 'Dear Ragani, You are very lovely and I love you dearly'. That's the kind of relationship we shared. So when she died, something inside of me died. I can now actually feel how a mother feels to lose a child. It was terrible.

Zanele described the hours leading up to her sister's death:

> The day she passes away, she called her kids and they came over, and she spent a lot of time telling them about HIV and how to take care of themselves and protect themselves against the virus. And after she was done…she didn't want to sleep in the bed, so they made her a place to sleep on the floor, and she got on the floor and she struggled to breath, and after a few minutes, she passed away.

Prudence had been sitting with her mother and her baby's father in a different section of the hospital when she got a message that a sister wanted to see her. She turned to her them and said:

> 'Mom, I know why they are calling me. My son is dead!' I told my Mom, 'Owethu has passed away and I can feel it'. My Mom and his father were right behind me. I wanted to say my last goodbye to him before he was taken away…it was very difficult.

The first emotion several participants remembering feeling was shock. Sibusiso was not with his brother at the time of his death. He was informed of his death by his brother's girlfriend. He said: "It was a shock even though I knew he was very sick. You see, you visit him in the hospital and they tell you he is doing great and the next day he is gone…He's gone too soon."

Doris's husband had gone to work that morning and she found out that night that he had died. "They (hospital) called but did not tell me he was dead. I found out from a friend of mine…He died at six o'clock in the evening." She couldn't believe what happened:

> After I found out, I called my mother-in-law. Then she came and we talked. We went to the hospital and couldn't view the body. They said we

> could not see the body because he had AIDS. That was the first time I found out he had AIDS.

Several participants felt that the way they were given the news of their loved one's death was not good. For instance, 15-year old Phumzile went to visit her stepfather at the hospital and returned the next day, but he wasn't in his bed. She became frantic and went from nurse to nurse but they kept looking away. Finally, one of the nurses went into the office and "checked the books and came up and told me that he had passed away." It was done in a very matter-of-fact way.

The ability of medical professionals to deliver bad news to patients' families depends to a large extent on their training and own background with loss (Saunderson & Ridsdale, 1999). A study of nurses in AIDS nursing care facilities in New York found that nurse aides had more negative attitudes toward people with HIV/AIDS as well as greater discomfort caring for patients who were dying than registered nurses (Demmer, 1999b). Studies are needed in the South African context that examine professional caregivers' (doctors, nurses, social workers) comfort working with AIDS patients who are dying. We also need to survey the level of satisfaction of AIDS patients and their families with regard to end of life care and bereavement support.

The Funeral

Funerals for young people have become routine in South Africa, as a result of the rise in AIDS-related deaths in recent years. Funerals function to meet the specific needs of mourners and society. There is little documentation in the bereavement literature about the therapeutic value of funerals from an African perspective. Most publications relating to funeral rituals are anthropological in nature, with little attention given to the psychological aspects of funerals. According to the Western perspective, the mourner derives a number of psychological, social, and spiritual benefits from funerals, as outlined by Rando (1984) (see Table 9.2).

Table 9.2 Benefits of funerals to the mourner

Psychological benefits
Confirm and reinforce the reality of death
Assist in the acknowledgement and expression of feelings of loss
Stimulate the recollection of the deceased
Social benefits
Allow the community to provide social support to mourners
Provide meaningful, structured activities to counteract the sense of unpredictability resulting from the loss
Spiritual benefits
Give mourners a context of meaning as they attempt to fit their loss into a religious/philosophical framework

[adapted from Rando, 1984]

Funerals also have important social purposes which are listed in Table 9.3.

Table 9.3 Benefits of funerals to society

Help the community adjust to the loss of one of its members
Affirm the social order that the community lives on despite the death
Bind members together through a shared experience of loss
Demonstrate to members that they themselves will someday die
Convey the community's values and beliefs regarding the meaning of life and death
Provide for the final disposition of the body or remains

[adapted from Rando, 1984]

There were two aspects of local funerals that were different from Western funerals. First, most participants reported that family members usually slaughtered a goat, and second, funerals were typically held on Saturdays. Otherwise, as Sibusiso explained, "We follow the Western custom now. The old men are dying now; they are no more there to give instructions....Funerals are not as elaborate anymore...Families don't have the money and there are too many funerals to pay for." Prudence remarked: "In our community there is nothing different. It's just the same – church service, cemetery, go home, and have something to eat." Felicity commented on changing traditions:

> I think they are just opening their eyes now. They can really see that this is a waste of money...If their older sister dies this week and they slaughtering a cow – next one dies and they say how are they going to get the money. So they end up really eliminating the cost.

Overall, the cost of the funeral was not an issue for participants because in most cases the deceased was covered by an insurance policy. Phumzile was the exception: at 15 years old, she had to make arrangements for her stepfather's funeral. Not only was this an extremely difficult thing for someone so young to do, but she also had to bear the brunt of anger and hostility from her stepfather's family, particularly his mother. Phumzile commented:

> In our culture, it's an elder person who goes to the hospital when the body is taken from the hospital. That person is supposed to say something to the body, so that the spirits of that person will go along with the body and when the body is buried, the spirits of that person will be there. So it wasn't for me, as a child, to do that job. I had to beg his mother to do this and to pay for the funeral. I had to beg her and beg her.

Usually AIDS was not mentioned at funerals and the "understanding" was that the deceased died of other causes. Sibusiso reported: "On the day of the funeral, I prepared a two-page speech, but my mother and aunt said, 'No, it's too long.' They hid my speech. I told them it was the last time I would see his body." Sibusiso had wanted to talk about HIV/AIDS in his speech: "I was trying to destigmatize it on the stand." He added:

> When you go to a funeral...you don't know if the person who passed away was due to HIV/AIDS...The pastor sometimes says...the deceased passed away because he was not taking care of himself: 'So many of you

> here will die the same way.' So that makes it more difficult especially for me to attend a funeral.

A number of participants commented on how many people turned out for their loved ones' funeral and how this was a great source of comfort for them. Sibusiso said that his brother had a lot of friends and they flew down from Johannesburg for his funeral: "There were a lot of speakers there and the speakers were most of his friends...They said he was like a leader to them." Ragani exclaimed: "Oh! The crowd! At my brother's funeral, we had over 1,000 people. We have a large family and lots and lots of friends...." For her niece, she said: "We also had a massive crowd because the entire school was there. She was in grade two. She was in a primary school in Phoenix. The entire school was there. You see, the school knew my family quite well." When asked if this had been reassuring for her to see this show of support, Ragani responded:

> Oh yes it was! And you know, you also have someone to give a little speech. I thought the most appropriate person would be her school teacher. Her poor teacher couldn't say anything because she was so distraught, because this was the first time she had lost a pupil of hers. She couldn't do it. Eventually, we got the school principal to do a little thing. So she gave the little talk about Shanni. It was quite nice.

But Ragani also experienced stressful moments at her brother's funeral:

> It became chaotic...There were a whole lot of delays to the point where they brought the wrong body to the house. Thank God, they didn't open the coffin. My brother noticed the wrong name...They exchanged bodies on the freeway – mind you! Such disrespect! My brother's body was on the way to KwaMashu.

A study of 74 bereaved individuals by Gamino, Easterling, Stirman and Sewell (2000) provided empirical support that participating in funerals and burial rituals assists in the psychological adjustment of mourners by facilitating social support and helping the mourner gain deeper levels of meaning with which to frame and understand their loss. However, what this study also found was a high incidence of "adverse events" that made the funeral rituals not so comforting. Examples included unresolved interpersonal conflicts between family members which erupted during the time of the funeral, disagreements over how the body should be disposed and problems with the funeral home and minister.

Conclusion

Because of varying degrees of awareness of the HIV status and prognosis of a loved one, few participants reported engaging in a process of anticipatory grief. For many, the death was quick and came as a shock. Some participants expressed regret that they could have done more for their loved one if only they had known all the facts. On the other hand, there were a handful of participants who had been involved for some time in all aspects of caring for the person as he or she was dying. What is interesting is that most participants accepted what had happened to their loved one, expressing little anger that the person died in actuality because of not receiving ARV treatments. The lack of "awareness" that prevailed around the time of the death continued at the funeral where the cause of death was not discussed. In the next chapter, we examine in more depth the secrecy and so-called lack of "awareness" that pervades South African society in connection with HIV/AIDS.

CHAPTER 10

Secrecy

In this chapter, I document the secrecy surrounding AIDS and deaths related to AIDS. The main reason for this secrecy is the high level of stigma and discrimination that exists in South Africa with regard to HIV/AIDS. In the current study, societal stigma determined the extent to which participants were open about their HIV status, whether they revealed the cause of a loved one's death, and whether they were able to share their loss with others. As we shall see in this chapter, most participants had to keep their own HIV status and the HIV status of the deceased hidden from others; hence the term "hidden grievers" (Dane & Miller, 1992).

Conspiracy of Silence

Silence about AIDS and AIDS-related mortality is evident not only at the governmental level as discussed in Chapter Two, but pervades the daily life of communities and families as well. Three participants commented on the silence that surrounds the epidemic in South Africa:

> Bathoko: "People are dying and not telling anybody!"
>
> Mthoko: "None of them are saying anything about what goes on…and they have family members that have AIDS!"
>
> Besta: "The community…doesn't want to talk about AIDS all the time. Even those who are really sick don't want to talk about it, so they only report or you see them at their last stage. People are never open about these issues."

When Nomzamo heard that her two sisters had HIV she was shocked because they had kept quiet. They only mentioned it when she told them she was HIV-positive. When someone dies of AIDS it often comes as a shock because people are not aware that the person was ill or that they had AIDS. Felicity remarked: "When you hear that somebody is in the hospital and just when you are preparing to pay them a visit, all of a sudden you hear they are dead."

Sizakele described how her family avoided talk of AIDS even though several siblings had died of it and several family members were infected:

> I think all of us, we're gonna die with this anyway, because two of us who are still remaining are suffering from AIDS. My other sister who is 27 is also HIV-positive but denies it. All of them, they are in denial...We talk about death, but the funny thing is we don't relate it to its real cause, because of the denial around it. So, every time there is a problem with HIV and AIDS, they will just look for something else to replace it as a cause. It's not real, even if we talk about it, because it ends up hurting other people's lives...When you mention a word about HIV, they will just grumble at you...it is like you have contributed to the pain that that person is feeling.

The silence around AIDS continues at the funeral service and long afterward as individuals mourn. No-one mentioned anything about AIDS at funerals, said Mthoko, and the only thing that was mentioned was the youth of the deceased. He blamed this on denial: "Families just don't sit down and talk about it. They only talk about it when the person is just about to die...This denial is ruining a lot of families." But he expressed ambivalence, saying that it was often not a good thing when families found out: "Sometimes it can destroy the victim's family when they find out about the HIV." When asked if he believed that it was better if the family found out earlier, he responded: "Yes, it is good for the family to find out earlier...but I do not believe it is good for the whole family." Bathoko summed up what typically happens - people will talk about their grief to some extent but not share details of how they died: "They don't want to talk about what killed my daughter. They'll talk about the pain of losing their daughter."

Muula and Mfutso-Bengo (2005) indicated that it was not clear cut whether or not people who come to a funeral should be made aware of the HIV/AIDS diagnosis of the dead person. An advantage of disclosure is the fact that mourners will realize that HIV/AIDS is real and that they can die from it. On the other hand, public disclosure "may result in a loss of dignity and potential shame for the deceased person's relatives" (p. 291).

Contributing Factors

Several factors account for this atmosphere of secrecy and denial around AIDS and AIDS-related death in South Africa, most of them associated with stigma. Participants felt that they could not be open about either their status or talk about AIDS-related loss primarily because of issues related to prejudice, shame, gossip, and lack of understanding. Other factors played a role such as family relationships and not wanting to burden others.

Stigma

The most common explanation participants gave for not sharing either their HIV status or their grief associated with a death from AIDS was the high level of stigma that exists in their communities. Campbell, Foulis, Maimane and Sibiya (2005) also noted the widespread stigmatization of AIDS in the Durban region when they interviewed residents in Ekuthuleni (a periurban area near Durban). Studies elsewhere in South Africa have shown that a significant minority of people hold stigmatizing attitudes toward people with HIV/AIDS (Nelson Mandela/Human Sciences research Council Study of HIV/AIDS, 2002; Peltzer, 2003). A street survey of 487 men and women living in a black township in Cape Town showed that 11% of respondents believed that AIDS was caused by spirits and supernatural forces and these respondents were more likely to endorse repulsion and social stigmatizing beliefs against people with HIV/AIDS (Kalichman & Simbayi, 2004b). In a study of high school pupils in the North West Province, highly negative attitudes toward people with HIV were reported (Strydom, 2003). For example, 64.1% believed that HIV-positive pupils should not be allowed in their school, 58.7% agreed that AIDS patients should be forced to place their names on a list in order that other people could be protected, 55.5% indicated that pregnant women who tested HIV-positive should be forced to have an abortion, 46.5% believed that AIDS was a punishment from God, and 42.3% were skeptical about having a meal with an HIV-infected person.

There is no doubt that AIDS stigma is an obstacle to HIV preventive behaviors (e.g. condom use), voluntary counseling and testing, seeking medical and other types of services once diagnosed, and the perception and treatment of people with HIV/AIDS by people in society (Brown, Macintyre and Trujillo, 2004). The culture of silence and denial that pervades South African society is perpetuated by the "head in the sand" policies of the government. Campbell et al. (2005) suggested that President's Mbeki's failure to adequately acknowledge and address the epidemic in South Africa is linked to his desire to impart an image of a "bright new postapartheid" South Africa. They explained that "AIDS and its association with promiscuous and diseased sexuality" is a threat to this vision (p. 810).

It is disturbing that even in countries like the US which has made enormous progress in HIV prevention education and treatment, HIV-related stigma is still rampant. Herek, Capitanio and Widaman (2002) reported the following findings from their national household survey on HIV-related stigma in the US: 12% believed that people with AIDS should be quarantined, 30.8% expressed anger or disgust toward people with AIDS, and 24.8% believed that people who got AIDS through sex or drug use have gotten what they deserve. Against this background, it is clear that those who are bereaved by AIDS in the US continue to be burdened by the stigma of AIDS. According to Kain (1996), the stigma of AIDS applies not only to the deceased but also to the survivors and this prevents them from "freely mourning" (p. 218). In a more recent U.S. study of individuals whose siblings had died of AIDS, Robinson (2001) confirmed that AIDS stigma persists, and "it appears to complicate grief for sibling" (p. 30).

According to Sprang and McNeil (1995):

> Some mourners may internalize the shame and stigma surrounding the death, leading to self-denigration, ignominy, disgrace, and a feeling of rejection, which may in turn lead to subsequent inter- and intrapersonal conflict. (p. 150)

Individuals bereaved due to AIDS feel the "sting of stigmatization" through lack of social support (Nord, 1997). There is no doubt that individuals in South Africa who lose a loved one to AIDS are likely to receive less support and sympathy than if their loved one died a more socially acceptable death such as cancer. The stigmatization of AIDS not only increases the pain and suffering of the bereaved but contributes to the social and economic vulnerability of those living in AIDS-affected households (Strode & Grant, 2001). The stigmatization continues even through death, according to some religious belief systems in Africa. In Kenya for example, an AIDS death is viewed as permanent in a way that other deaths are not. According to Nzioka (2000):

> Those who die of HIV/AIDS are equated to those who hang themselves. Death from HIV/AIDS is of particular concern because it does not just threaten to annihilate and tarnish the individual's identity, but also to do the same for family, clan and community. (p. 6)

Blame

The stigmatization of HIV/AIDS that was reported by participants appeared to be supported by several beliefs, one of which was the link made by many people between HIV/AIDS and promiscuity. "People don't want to talk about it," said Nomzamo, "because of the route of transmission. Because it comes through sex, people will think you are promiscuous." Similarly, Felicity explained that "people think you are sleeping around with many people. To them, once you are HIV-positive, it means you are a prostitute." Zanele wished that she could talk about her deceased sister to others but she could not, fearing that they would think her sister was promiscuous. She lamented: "People make no attempt to understand because they are not going through this." Sibusiso recalled when he first disclosed his HIV status:

> Some of them were shocked that I am HIV-positive and some of them said, 'He deserves to be HIV-positive – so many kids, so many women in his life! They blamed me…I tend to ask myself, 'Why am I still disclosing to this community, why am I trying to help them?'

Nomzamo noted that even some home-based workers were prejudiced and she had overheard them telling patients "'You got this because you slept around'." Tuli commented that people would be less judgmental "if they know that they are all at risk…not just the promiscuous people….They don't realize that already so many people around them are HIV-positive. They don't think like that, they don't." According to Delarise, "people need to be more committed and realize it might not be at your doorstep today, but it can be there tomorrow at the rate it's growing." Sizakele felt the same way:

> I think people are not empathetic enough. Every time you see somebody dying there, you don't even imagine yourself or anybody around you being in the same situation….To me, it so silly, because out of 10 families, its one family that is not being affected directly.

Because of the hostile environment, several participants kept quiet because they feared what people would do. Bathoko said: "I think that we have to talk, so that we can get help. You can't get help if you are not talking. But sometimes if you talk you get hurt!" Similarly, Zanele refused to tell anyone about her HIV status or how her sisters died because she was concerned for her children. Monica remembered conversations with her friends about HIV and how they would say "'If someone gets HIV at home, you just chase them out - we don't want that!'" She added that "people don't come out because they are scared people will fight with them…so that's why they just keep quiet." Muula and Mfutso-Bengo (2005) warned that people need to be very aware of the potential harms associated with public HIV disclosure, both to the individual and the family. When a person or community hears a public disclosure, this could cause distress in them and they may retaliate.

Demonization of Women

The unequal treatment of women in South African society and their vulnerability to HIV/AIDS has been well documented (Karim, 1998; Leclerc-Madlala, 2001; Ackermann & de Klerk, 2002; Kalichman & Simbayi, 2004). Participants felt that community members judged women harsher when it came to AIDS and they worried what people would say when they found out that their loved ones who were female had died of AIDS.

Sibusiso noted that in a family if the person dies of AIDS there is a different reaction. Males are labeled "playboy' while females are given the more derogatory name 'bitch'. Sibusiso reported that "the man is supposed to have so many women...but women are not allowed to share two men." He justified his large number of sex partners by saying: "I've inherited my father's genes. He loved women...Maybe one month, I'll be 'quiet'. But then someone will say that woman wants you."

Delarise described the way people treated her when they learnt she was HIV-positive:

> People do not readily accept you. They look at you like a sexual leper. She had to have been promiscuous! The most insensitive question people ask is, 'Delarise, where's the man that infected you? Would you know who gave it to you?' And I always say, 'Do you really believe I woke up one day and thought about it and said, 'I'm going out to get infected today'...Stop worrying about 'who' and 'how', it's too late for that...I need love, understanding and that's what you should be giving me. Not 'who', 'when', 'why'! People ask that because they want to feel in a position of superiority...They also think they are forcing me to confront my sexual past, so they are in a position of power. I always tell them I don't allow an 'alleged' HIV-negative person to be in a position of mental superiority or power over me.

Stigmatization by Family Members

Several participants were particularly hurt when they could not talk about the cause of death within their own family. Nomusa was never able to tell her family that her nine year old daughter had died of AIDS. She reported:

> Due to the fact that I am the only girl at home, I couldn't speak to them. Also, their attitude to HIV and AIDS...I could see they didn't even want to associate themselves with it. So, I just decided to keep quiet. The day

> she passed away, they looked in every drawer until they found what they were looking for. I cannot say they did not know but nobody spoke about it. I did not want to tell them because I could see them behaving badly and their attitude toward AIDS. They were so eager to know but they didn't have the courage to ask.

When Prudence's infant son was dying of AIDS, she told her mother but not her father. Prudence did not open up to him "because he does not understand anything about it. My Mom and I decided that we have to keep it down for a while." She felt that no-one would suspect anything because although her baby "was very ill, he never lost weight. That is why it was very difficult for other people to know what was going on with the child." That was three years ago, and to date she still had not told her father how his grandson died.

Bathoko also believed in being careful about which family members one confided in: "You can't tell everybody...I just can't tell anybody just what I feel." Delarise discussed a possible consequence of disclosing to one's family:

> I know about a 38 year old white guy whose family put him in an old age home because they were embarrassed. That me so angry...He died alone in a caravan park in the beginning of June, by himself. His family put him in a caravan park because he burnt a carpet in the home, and although they were rich, they didn't want to pay for his room.

Church

Despite the fact that most participants reported great faith in God, which I discuss in Chapter Thirteen, many were critical of the church's handling of the AIDS crisis and they felt that churches perpetuated the silence surrounding AIDS-related deaths. The most common complaint was that church leaders spewed hatred toward people infected with and affected by HIV/AIDS and they refused to talk about AIDS when conducting funerals of people who died of the disease. Bathoko reported negative experiences with the church: "In the churches, they are talking about this HIV thing badly – shame!"

Monica said that she didn't attend church regularly anymore because of the hostility she encountered toward people with HIV/AIDS:

> The priest…didn't talk nice about people with HIV. He said: 'If you are here in my church and I know you are HIV positive, you no more come here in my church'… I don't trust any churches.

Besta who was a regular churchgoer never talked to her pastor about her HIV status and reported that the church never talked about HIV/AIDS. "Every church has forgotten to be human that is the problem," Delarise commented. "Every church should start educating every person in their church." Felicity felt that she had to tiptoe around HIV/AIDS at her best friend's funeral:

> These people really need to face HIV because I remember they asked me to stand and say something as a person who knows her at the funeral. I mentioned the HIV thing but I didn't say she died of HIV. I spoke about HIV, that everyone should know their status, you should go for a blood test if you don't know…So I told everyone that it is very important because we can't keep on burying people and maybe assuming that they died of HIV or do we know but don't want to talk about it.

Almost every participant reported that there was no acknowledgement at funerals by either the church official or the funeral participants that the person died of AIDS. Everyone would participate in pretending that the person died of other causes, such as cancer or heart disease. Prudence commented:

> People don't understand that death is the same whether it's HIV or cancer…Sometimes, if a person dies of AIDS, they don't usually say 'so and so' had full blown AIDS – they say 'so and so' was a diabetic or 'so and 'so' had cancer. They don't want to say 'so and so' died of AIDS.

Campbell et al. (2005) also noted such a "conspiracy" among family members of the deceased in Ekuthuleni, whereby no-one strayed from the "official story" that the person died of something else even though everyone was secretly aware that the person died of AIDS.

Two participants who were HIV-negative said they were unsure how people with AIDS would be judged in the afterlife. Tuli said: "I think nobody deserves to die....I believe it is a matter between the person and God." When Felicity was asked whether she believed that people with AIDS would be treated differently than people who died of other causes (e.g., cancer), she replied:

> That's a tricky question, but I don't think so, because sin is sin. When you sleep with someone and get HIV, it is sin. I think it is no better sin because even murder is sin...I once read the scripture that says that there will be dreadful diseases, diseases that cannot heal. But it goes on to say if you ask for forgiveness, you will be healed. Cause cancer is sickness as well as HIV, I think there is no better treatment. If 'they' are supposed to be judged, I think they will be judged according to what they have done.

Shame

Some participants clearly had internalized the stigma and expressed shame that they were HIV-positive or that their loved one had died of AIDS. Words like "ashamed", "disgrace" and "dirty" were frequently mentioned by participants. According to Prudence:

> In African families, they take it as if you are a bad person if you got AIDS....They think maybe you deserve it. The funny thing is that they do not want to go get tested for HIV....I think that is why many people are dying; because they do not want to test.

Ragani explained how her family tried to hide their "dirty" secret about her brother having AIDS:

> What happened was in December, just before he died, he was given a pass out of the hospital because it was his baby's first birthday. So, he came home and we decided to have this great big party and that is basically when he told us (that he had AIDS). He also made us promise that we would not tell anybody about it: 'Please don't tell anybody!' It's a thing among Indian people that if you are HIV positive, then you are ostracized; they don't want to know you because AIDS is a dirty disease as far as they are concerned. People look at it in different ways. So, amongst us, we decided we were going to say it is cancer and leave it at that...My mother did not want to tell anybody about it and my sister-in-law as well. She didn't wish for anybody to know especially her family – her mum and dad as well as anybody else...My stupid sister mentioned it to somebody who mentioned it to somebody and then everybody knew. But we didn't know everybody knew (laughs)."

Gossip

Just as Ragani mentioned, many participants were reluctant to talk about AIDS or their loss because word traveled fast. Zanele said that people don't share their feelings "because one person tells another and another and the next thing everybody knows." Mthoko said that it was advisable to reveal one's status or the cause of death only to certain family members: "You cannot trust everybody...you realize that people, they drink, and once they are drunk, they just speak about it and tell everybody." Azon said he had a few close friends but he didn't talk to them about his health: "No, never! – because they will tell people, I keep it to myself." Likewise, Tuli could not trust her friends and talk to them about her sister's death: "I didn't trust them enough...I couldn't mention it because of the stigma. I told them the doctors had made a mistake with the operation, so that's what they understood." Mthoko said: "You know, sometimes it is very hard to trust someone and try and share...you don't know when you are finished sharing with him or her, who else is going to find out."

For most participants, with the exception of Delarise who was very defiant, it was important what other people thought about them. So, they did everything they could to prevent neighbours and others from gossiping about them and, as Sizakele said, "leave the bad stigma on you." Both Prudence and Bathoko were hurt when people talked about their HIV status. According to Prudence, "when we walk on the streets...we know people are talking...it makes you feel uncomfortable." And Bathoko said: "I can't tell anybody that I am HIV-positive because people are gossiping. Sometimes if you don't feel well this morning, they will say, 'Oh look, she's nearly dying now'. And those things are discouraging."

Drawing on ethnographic research in the Bushbuckridge region of the South African lowveld, Stadler (2003) suggested that "rumor and gossip are powerful channels through which people talk about HIV/AIDS" (p. 366). He added that they represent a means to control the epidemic and they can be viewed as metaphors that challenge biomedical constructs of AIDS.

In a qualitative study of HIV-infected adolescents in the North-West Province of South Africa, Strydom and Raath (2005) indicated that 14 of the 17 adolescents who had told others about their diagnosis had experienced some form of discrimination from family, friends or in their school and "a number of respondents also recorded gossiping about their illness that led to even more rejection by the community" (p. 574).

People Don't Care

Another reason participants kept silent was the perception that people did not care. Zanele noted: "Neighbours pretend to feel sorry for you when you are grieving, but the fact is once you're out of sight, you're out of mind." Similarly, Bathoko said: "I don't think it's because they don't want to talk - maybe it's because nobody is interested to hear about it."

Besta volunteered as a community based worker helping people with HIV/AIDS in her community. However, she reported that her own family was not happy about this and they were "very negative about this whole thing of taking care of other people. They think I will get the virus from helping, so they are worried." Some community based workers were viewed with suspicion because they would visit the sick person and then shortly after the person would die. Thus, they were seen by some as hastening death.

Besta was disturbed by the callous way people treated their loved ones who were dying of AIDS: "You even see it in their actions," she said. "It's like they are not aware of HIV/AIDS. It hurts me that when someone is dying like this and someone doesn't care. It really hurts." Home-based care has become an important part of the strategy to care for people with AIDS in Africa, yet Olenja (1999) reported discouraging findings in terms of negative attitudes by family members toward persons with AIDS and a lack of training and limited resources among families to care for their own.

Don't Want to Upset Others

Muula and Mfutso (2005) suggested that individuals need to carefully consider if, when and how to publicly disclose their HIV status or that of the dead person. Individuals should be aware of the benefits as well as the potential harms of such disclosure, and the community needs to be "prepared to receive such a disclosure" (p. 294). Several participants were hesitant to talk to their family members about their loss out of concern that they could not handle the news or would not know how to react. For example, Azon never spoke with his two daughters about their mother's death as "I'm worried it might upset them." One reason why Doris did not tell her children that their father had died of AIDS (even 10 years later) was that "I did not want them to worry about me. They didn't know what was going on in the bedroom. At the time, I didn't know anything about AIDS." Zanele thought that people didn't know how to approach someone who was grieving "so they just leave it alone."

Mthoko had not told his mother that he, like his deceased brother, was HIV-positive, because he worried how this would affect her, especially because she was elderly. "She is an old person now," he said, "and once she takes on something like that, she can no longer go on and collapse. I thought it's not good to tell her..."

Traditional Beliefs

Several researchers have commented on the importance of examining indigenous representations of AIDS including the role of traditional healers and viewing AIDS through the “witchcraft paradigm” (Ashforth, 2002; Liddell, Barrett, & Bydawell, 2005). About half the participants were aware that some people believed that AIDS was due to witchcraft but they did not take these people seriously. Nevertheless, this was a factor they considered when thinking about sharing their loss with others. Prudence and Sibusiso commented that this type of thinking was an excuse not to deal with the truth. Prudence said: “All this stuff - people believe in it, because they don’t want to accept reality – they are denying everything about HIV and AIDS.” And Sibusiso said “these things confuse the community. They run away from the truth. This is the thing that is killing most of us.”

Only two participants, Felicity and Sibusiso mentioned that they knew people who believed “conspiracy” theories that blame agents such as Dr. Basson, soldiers, and governments for the epidemic. In a recent study of Northern Sotho and Tsonga speakers (35 men and 35 women) in the South African lowveld, Niehaus and Jonsson (2005) observed differences between men and women in terms of the attribution of blame for HIV/AIDS. While women tended to blame men and nurses for the spread of the virus, men invoked conspiracy theories and the researchers suggested that men held these beliefs because of changes in the global labour market and job losses.

Tuli and Delarise were adamant that many people did not know how to handle individuals who were experiencing AIDS-related loss because they were truly ignorant of the disease. Tulu felt that people didn’t share their grief with others “because of lack of knowledge…If you really don’t know what this HIV is, how it happens, you keep quiet.” When I asked Delarise what families needed after losing a loved one to AIDS she replied without hesitation: “They need education. They need answers to many things because they are so full of guilt. They never bothered to get educated about it.”

Past Hurts

Abandonment issues stemming from the past shaped several participants’ willingness or ability to reach out and talk about their loss. In particular, Phumzile, Sizakele and Tuli painfully recalled how they were treated as they were growing up and how unloved they felt, even today. Phumzile reached out to her biological father after her mother and stepfather died of AIDS. She had not been close to her mother, even up until her death.

When Phumzile was growing up, she did not realize that the man living with her mother was not her father. What had really happened was Phumzile's father had deserted her and her sister at a very young age. Her mother subsequently remarried and never told the girls. Looking back, Phumzile realized that her mother had always made her feel responsible for her real father leaving. After both her mother and stepfather died of AIDS, she sought out her father and eventually she located him. She recalled:

> I was so anxious to see how does the man, who is my father, look like. Who is he? How is he going to react to seeing me when I show up to him? I was so happy to see him. This is my real father...I had that hope that now I would find the love I've been longing for. Everything's going to be alright. Little did I know, of course. I was so hopeful...

While the meeting went very well and was emotional for both Phumzile and her father, regrettably nothing else came of it and she had not seen him since. Disappointed but not altogether surprised, she remarked:

> He never asked, 'How do you live? How do you survive?' I would be happy if he could send me R100 a month just to show – I know it's not much – but to show that he cares. But he's not doing that, so it's like nobody loves me, nobody cares. I'm just like something which shouldn't have happened in the first place.

Sizakele and Tuli also described feeling abandoned both in the past and still today. "I was born into a broken family," said Sizakele, "and I was born out of the marriage...I had no sense of belonging. I didn't know where was my father or mother. I was abandoned." When asked if she still felt a sense of abandonment, she tearfully replied:

> Yes. Because as much as I am an adult and I can take care of myself, but still you need people that you belong to, to be around you. Even when you visit them, you could see that you are a total stranger, and it doesn't

> give you any joy...I will live with it till the day I die...There is no bond with my other siblings because we did not grow up together.

Sizakele said that the death of her sister-in-law affected her more than the death of three siblings to AIDS. The reason was that her sister-in-law had broken the family ban on having any contact with Sizakale. She sought Sizakele out to ask her if she could take care of her as she was dying - not trusting any of the other family members. This made Sizakele feel good that a member of the family had reached out to her, even if it was to obtain help. Sizakale went to the hospital and was shocked to see her sister-in-law so ill. She reported:

> She told me that she's got no money even to go home. She's being discharged but nobody is going to take care of her and she can't go home....She said that she regrets every word that she had uttered to me. She said that she feels that I will be the better person to take care of her...We reconciled. I said, 'Listen, I've got no grudge against you.'

When the family found out that her sister-in-law was dying of AIDS and that she wanted to go live with Sizakele, they were bitter and they told the sister-in-law: "You must tell her she must stop calling herself our family because she doesn't belong to this family and she must go to the place where she got this virus from."

Sizakele not only had to deal with her own status and the loss of so many family members to AIDS in recent years, but she also had to deal with her alcoholic husband who was a major source of stress in her life. Her ability to grieve or talk about her losses was hampered by her relationship with her husband and his failure to support the family. She said: "It's very difficult at home" and added:

> My children say it would be better if...he had passed away...because they don't understand why they're so suffering with him...Everything depends on him but then he is not there for us. How is he expecting us that we'll be getting the money? And he will...expect that I will do something to

> make ends meet…I wish I could just leave and run away. I wish I could wake up with so much money and take my children away.

Tuli carried deep emotional scars from the past as well, but was reluctant to delve into this during the interview. All she said was that she grew up in her uncle's house and that she felt that her mother was "just a relative." She never talked to her mother about her deceased sister. Her mother never contacted her to ask her to come and help care for her dying sister. Tuli said: "No, she never did that because she felt that I don't really belong to her." When I asked her if she was resentful of her deceased sister, she responded: "Maybe, because she was always there for her and not for me." When asked if she had any good memories of her sister, she replied: "No." They didn't grow up together.

Doris and Ragani also reported ambivalent relationships with the deceased. Doris said that she was not close to her husband before he died because she had discovered that "he was having extra-marital relationships". Yet, she said: "There was no hostility - it was a casual relationship. I was very close with my in-laws, and I never hated him." Ragani was angry at her mother for "spoiling" her deceased brother as well the other brother who was still living with her. She blamed her for the way her two brothers turned out. Two weeks before our meeting, Ragani discovered her father's diary for 1982, the year before he died. She said:

> In his diary, he wrote something which made me realize how irresponsible both my brothers have been. They never took responsibility for their lives and always relied on my Dad and Mum. They realized that if they can't do something, somebody else would do it for them. It makes me now look at them in a totally different way. I knew my brother as someone who took charge of things, but he really didn't. He was my big brother…I looked up to him, he was my role model - but he actually wasn't.

Finally, Felicity described the death of her two-year-old child in 1997 and how she was determined not to feel the same pain when she lost her best friend from AIDS. The child had died suddenly (of cardiac failure). She said:

> It was my first child...Nobody could comfort us. People said a lot of things but no-one could close the gap that I had...No-one could really understand, we were like mad...We didn't believe she was dead...So, it took very long, I don't want to lie....

She said it was only in 2002 that she started to feel normal again: "I cried and cried and cried – the voice said to me it is for the very, very last time."

Conclusion

In this chapter, I have described how participants were forced to become "hidden grievers". Secrecy and stigma dominate the South African landscape and not surprisingly most participants were unable to openly share their grief with others and to disclose the cause of death of their loved one. Because of fears of being ostracized by others, the bereaved in South Africa may have to censor their interactions with others and mask the truth, so that others do not have to deal with the reality of HIV/AIDS. And the question is at what cost to the bereaved? It is indeed unfortunate that we have a culture where both the dying person and their loved ones are commonly denied the opportunity to be honest with one another – even at the end of life. In the next chapter, the issue of social support (or lack thereof) is examined.

CHAPTER 11
Support

Having learnt in the previous chapter that the overarching culture of denial and secrecy in South Africa prevented many participants from talking openly about issues relating to HIV/AIDS, dying and grief, the next step is to find out their perceptions of the kind of support that was available to them. This chapter describes formal or institutional support (from the government and welfare organizations) as well as informal social support from family, friends and neighbours.

Formal Support

Government Policies and Actions

Much has been written about the government's management of the HIV/AIDS crisis in South Africa. According to van der Vliet (2004), President Mbeki has been unable to deal effectively with the HIV/AIDS epidemic in South Africa because of his "hypersensitivity to criticism...and his suspicions, some say paranoia, concerning the pharmaceutical industry, the media, and conspiracies aimed at him and his government" (p. 88). When asked what they thought of President Mbeki and his government, a large proportion of participants felt that he had failed to deal with the epidemic properly. On the other hand, a few tried to provide explanations for his government's response and they were more understanding. Some thought that the government was actually doing a satisfactory job addressing the epidemic. These views are described below.

Doing a Poor Job

The governments' policies and actions made many participants quite angry. Participants like Zanele, Ragani, and Delarise felt that the government had done very little. On President Mbeki, Doris said: "He has taken too long. He has known about the problem and he has too many excuses." Ragani remarked:

> They haven't handled anything. The President of our country doesn't know anything about AIDS. He doesn't seem to care. We are your people. People are dying and he doesn't know anything. He is horrible and sick. They spent R60 million on the democratic party when the ANC won the elections. That money could have been well spent on ARVs for people who are dying and suffering.

Similarly, Delarise said:

> I find it disgusting. That you could wait almost 10 years and prior to election you suddenly start to give out ARVs...The government let people die for so many years and suddenly people are voting for them and thanking them for this...They're doing zilch.

Participants gave examples to support their statements. Zanele said: "They say they are giving us antivirals, but whenever you go to a clinic, they don't give them to you. They just treat whatever infection you have at the time and tell you to go." Bathoko complained that she did not know which hospitals were providing ARVs, while Delarise said that "it's only in three hospitals." According to Ragani, "They are dragging their feet. They haven't done anything in this province yet...They haven't even trained any staff yet in terms of administering the drugs."

Additional criticisms centered round the fact that funds were not going to the people. Both Prudence and Delarise commented on the lack of HIV prevention efforts in rural areas. Prudence noted:

> People are getting funds, even the government is getting funds, but it doesn't reach the people. They are suppose to teach people and teach counselors to go to rural areas to teach people about HIV but they are not doing it at all. I think they are not taking the illness very seriously.

Delarise remarked that "if you go out and look at rural HIV education programs, they're disgusting." Prudence also commented that people have to wait a long time to obtain their grant money: "I have waited months and months and maybe if I go check they say, 'Come back in December'. They usually do that."

Several participants lamented how many people had already died because they did not have access to ARVs. Nomusa who lost her daughter sighed and said:

> If only they had done it sooner, it would have made a huge difference, because a lot of people have died...If only they had done it earlier, people like my daughter would have been saved. So I don't want to be angry because I am going to end up in trouble and it's not going to help me (laughs).

It was hard for participants to comprehend why the government acted the way it did. As Felicity mentioned:

> The thing that I hate about the government is...why can't they just give people the drugs. I have been listening to the Minister of Health. She has been talking about drugs and they say it's expensive. When I look at the government, they have a lot of money. Why can't they help? It's so sad to see millions of people dying."

Zanele said that "if so many people are dying, they should be hurrying and speeding up the process." Besta complained that the government gave mixed messages to its citizens: "It's just confusing. The government promises there would be a cure but no cure. And now they say that the cure would be dangerous." It also made her sad that some people could get ARVs while others could not.

"I think we should stop talking and start doing," Doris said. "We need to follow Uganda's lead." And Nkosi remarked: "If the government could just pull up its socks, things would be much better."

A lot of hostility was directed at the health minister, Dr. Manto Tshabala-Msimang, whom some participants considered a puppet of President Mbeki. Delarise commented: "I think she follows the President...she's not good; she doesn't come across well. I think she messes up and stumbles and I don't know who advises her." Doris said that she disliked the health minister a lot while Azon thought that she "talked nonsense." Overall, many participants did not feel that she cared about people with HIV/AIDS. Besta remarked: "She used to talk nicely but never promises anything." And Prudence commented: "Oh. She doesn't care about how many people are dying everyday of AIDS. She just wants to do things in her way in her time." When asked how people in the community felt about her, Prudence replied: "They don't like her. They don't like her. Everyone is complaining. I didn't expect her to be re-elected."

Trying to Understand the Government's Response

Some participants took a more tolerant approach and attempted to offer reasons for the response of the government. These are described below.

Other priorities. Several participants felt that the government should not be judged harshly as there were valid reasons for its policies. Tuli and Sibusiso commented that in the past the government had other priorities after it came to power in 1994, such as building democracy. As Tuli explained:

> I would say our government is new, so I think they had to concentrate firstly on creating the democracy...and then...as I see it now, they are more concentrating on the AIDS...because the first 10 years they had to concentrate on leading the country

Sibusiso said: "In South Africa, after apartheid, we have had 10 years of democracy and people expect things to happen overnight. But, they have budgets and they are taking good care of us."

Scientific reasons. Some participants believed that the government had sound scientific reasons for not rushing ARVs. Phumzile said: "I think there had to be time to build research on medication to find out if it can make a difference." Sibusiso added: "How can you give people something you don't know about? They have to do a research and a study about the side effects and then tell people about it."

Need to educate people first. Several participants believed that it was essential that the government prepare people properly to take the ARVs before they could distribute them. Nomusa, who wished that ARVs had become available sooner, also saw the need for the government to be careful. She said:

> I think they are doing a good job through rolling them out slowly because people are going to rush into taking ARV drugs and maybe not taking them properly and they end up not being properly trained. They have to be properly trained before they roll them out.

Similarly, Tuli said: "We cannot talk about ARVs if you don't educate people about how they get HIV in the first place - because people think if they get those ARVs they will be cured. So we need to educate them." Prudence added that many people, herself included, would not adhere to the treatment. She reported:

> You know, at first I think the government wasn't really handling this mess very well...now I understand the message...I've noticed the government is really doing something – because you can't give medication to anybody...You know, like myself, I am not very good at taking a treatment....This is the main reason I know now that the government is being careful...I've seen it in a different perspective.

Phumzile added that "you cannot give ARVs to people who are hungry. They have to be fed and then given the medication."

Not the government's responsibility. Sibusiso and Mthoko did not think it was fair to blame the government because it was the individual who had brought it on him/herself and became infected. Sibusiso elaborated:

> I feel they are doing a great job even though many lives have been lost, like my brother, my aunts...I don't blame the government. One must blame oneself...Why should I shift the blame on someone else when I have the problem. The South African government has done a great job, even if they distributed them this year. Maybe it was one of the strategies to use in the election because everything that is happening has a political agenda.

Mthoko added:

> What can I say? I cannot blame the government because they are trying something. They cannot help the whole world...I cannot comment on how quickly they do it. I cannot blame the government because if you keep something a secret, it is hard for anyone to help you.

Things are Improving

Another group of participants felt that the government was doing a decent job and that progress was been made. Azon commented: "It is starting to get better than before. Before, they didn't want to hear anything." Sibusiso, who belonged to an organization for people living with HIV/AIDS, firmly believed in the commitment of the government:

> The government has provided what the people have always cried for – the ARVs. And some of the food parcels have been distributed to those who are very needy....Even in the pharmacies, the prices are dropping because of the government. I think he is trying. Now people are not dying so fast...For me, they've done their share...Pamphlets are being distributed all over. They are showing their concern and acknowledging that

> HIV/AIDS victims are also human beings...They are distributing these ARVs. They do care.

What the Government Can Do Better

Although they were aware that some progress had been made of late, most participants firmly believed that more needed to be done. Mthoko predicted that "it is going to take some time to get the right help." Besta and Felicity worried about how money was wasted. Besta said that many parents use their child grants to buy alcohol. Felicity believed that the government should focus more on treatment and less on giving out disability grants to people with HIV/AIDS. "They are spoiling them," she said. "Once you are HIV-positive, you are placed on disability. You earn R750 per month. You sit there doing nothing. You keep on smoking and drinking." She suggested that the government rather provide "food parcels and medication than giving them money." Zanele felt that grants needed to be disbursed more efficiently:

> HIV-positive people should be given grants so they can survive. When I applied the first time, I had to wait seven months and then another two months, and when it finally came they only reimbursed me for 3 of the 9 months I waited.

Other suggestions were for more HIV/AIDS education in schools and stocking more medicines in clinics and hospitals. Besta emphasized that "the government has to give treatment – not wait till people are in the last stage."

Welfare Services

Besides health care and medications, participants also voiced opinions about the quality of social welfare services provided by NGOs and the state welfare department for people affected by HIV/AIDS. Although they felt that there were enough local organizations available to help people with HIV/AIDS in Durban and surrounding areas, many participants did not regard them very highly. A common perception was that local NGOs were only in it for the money. Tuli commented that "they are not doing the service to the people. They are only concentrating on getting the funds – not helping the people." Likewise, Felicity said: "I hear a lot about millions and millions of dollars that have been put towards HIV and AIDS, but there is nothing that is happening. People are really making money out of HIV rather then helping people at grass roots." Prudence added that "there are some NGOs that are just not doing anything at all. They are driving big cars but they are not helping the poor."

Most participants felt that organizations did not work together. As Monica remarked, "I think everyone is working on their own side." Ragani said that organizations "do not pool together because they have problems with each other. Each one wants to be private and on their own, which is silly."

When asked if people knew what support services were available to them in the Durban area, participants typically answered no. Ragani exclaimed: "It is the duty of the social welfare departments to make themselves known; be approachable, be user-friendly – and they are not." Participants commented that even when people knew about services they would not seek them out. Nomusa explained that "people in the community don't want to see anything to do with HIV...It's those people who are still ignorant and still have not come to terms with their HIV status." Phumzile agreed and said:

> Most people when they find out they are actually HIV-positive, they just lock every door in their life and they shut out every information they need. First, they deny and secondly they don't want anybody helping out. People are afraid to get services because they are afraid of being seen or their neighbours finding out. There is so much stigma.

Informal Support

Participants were asked about the extent and quality of social support they received from family and friends after the loss of their loved one. Some were fortunate to have one or two people who they were able to confide in, while some belonged to a support group for people with HIV/AIDS and they gained support through this venue. Prudence, Zanele and Bathoko got support from their mothers, while Nomzamo and Mthoko relied on a sister. Nomusa said (smiling): "My daughter is one helluva emotional support...She is the one person who loves me for who I am." Sibusiso, Sizakele, Prudence, Nomusa said that they occasionally got support from members of their support group but it was mainly about being HIV-positive.

Absence of Support

On the whole, participants felt that they did not get much support for their grief, from either family members, friends or neighbours. Besta commented:

> Mostly, in the family, even if you want to share something, they ignore you. They don't listen to what you want to say." "We don't talk about serious things...It hurts the children, the nieces and nephews...They are all dying (family members) and they are so young and they never talk about it till it's very late."

Nomusa had not expected any support from her family "so I won't be disappointed." Nevertheless she was hurt by the way her brother and his wife had treated her:

> I remember a time when he and his wife –he would buy food and cook in the smallest pots in the house and they would cook for the three of them – my brother, his wife, and their daughter. Nothing would be left in the pot for myself and my two daughters. I would try by all means to find food by myself; I was battling...And what makes me even more angry - now that I have some sort of income, they have become 'friends' of mine. In fact, just this morning, I got a message from her, asking for money. I am going to give it to her. If I do have money, I give her. I don't know how because I don't have much. I start getting very emotional about it. In fact, I don't know if I am ever going to get rid of it."

Most participants reported feeling lonely. Nomusa, Phumzile, Zanele, Besta, Prudence, and Nkosi said that they did not have any friends at all. Nomusa said nobody had ever "bothered" to ask how she was feeling after her daughter died. Three other participants (Phumzile, Nomzamo and Bathoko) commented that nobody was interested in their grief and that people didn't want to talk about it.

Neighbours could also not be counted on. Both Zanele and Bathoko said that you could talk to your neighbours but you can't tell them about your problems per se and if you did, you were not going to get any help." Nomzamo reported that in her area, "no-one helps their neighbours". Bathoko warned: "They like to talk! You can't go to somebody's house and ask for help – they would say it's your family's problem."

Nkosi said that he could not trust anyone. He recalled how people in his area laughed when they saw him crying:

> To me, it is very sad if my mother passed away and people keep laughing at me...I have learned one thing...that I cannot trusting nobody in this world...I cannot share my problem...Maybe I can come and tell you my problem and tomorrow you will look at me and harassed me. I think that reason why that makes me keep thing inside of me.

Phumzile also felt ostracized by her community and reported:

> I just discovered something - that some other women around my home...I don't know if they envy me or what – but I found out that they don't really like me. Most of the women around my home – they are not married but they are staying with their men. And I am all by myself at home and I think they feel a little insecure...They know the hell I have gone through and I am still surviving and I still look like nothing is wrong with men...like nothing has ever happened to me...I feel they are jealous of me. And maybe the way their men look at me and know that I live alone and that I have no boyfriend...I know how they feel about me. But I pretend as if I don't see.

She tried to put a positive spin on things and said: "I look at other people's lives...and if it's positive, I take it for myself...I try to throw on positive things and take it for me and it works."

Stajduhar (1997) conducted in-depth interviews with family caregivers of people with HIV/AIDS in Canada. A theme that resonated among these caregivers was the importance of social support. Participants complained about unsupportive interactions with other family members as well as professionals such as physicians, nurses, and social workers. The participants felt that supportive networks could have aided them in finding sense in their loss.

Inappropriate Comments

Several participants recalled insensitive remarks made to them, usually at the funeral, by people trying to comfort them. According to Tuli, people said things like "She was in pain. At least she is relieved." When Prudence's infant son died, a few people told her things like "You must not worry – God has done what he wanted to do" and "You are going to have another baby." Sibusiso also remembered "useless" statements such as: "'Be strong", "It was bound to happen" and "We'll all leave this land". Nomusa reported:

> People said weird things. Actually, some said: 'Oh, why worry that much because you knew that time was going to come that she was going to die.' Also: 'Why worry that much because you have got another one.' Those kinds of things. I just decided to ignore them because truly a person can say whatever they want to say and try to help you and deal with the pain you have, but they will never know what you are going through. But I just said, okay, I am going to take whatever I think is going to help me and pull out what I know is not going to help me.

Ragani felt utterly neglected despite having cared for her dying brother, his wife and their child. She said:

> The only words of 'comfort' I got was: 'You've got to be strong for your mother and your kids. Make sure you don't cry in front of them, and if you do cry, go to the bathroom and have a good cry.' Yes, those were my words of 'comfort' from everybody, which was sad! Nobody ever respected me and the way I was feeling – because I was really distraught. Sometimes, I really wanted someone to tell me, 'You wanna cry, just cry. I'm here for you.' No, I never got that.

Differences between Men and Women

It was not surprising that women were perceived to be the ones who were more likely to talk about their grief. Nomusa remarked:

> In support groups and workshops, there are a lot more women than men. Men tend to ignore things. When they experience the loss of a loved one, they tend to do drugs and drink. They always try to find something that will remove the pain.

Similarly, Besta said that "men are not like women. They don't feel the pain…While the person is sick, they just ignore the situation. Women…want to face the situation – not ignore it." Sibusiso gave his male perspective:

> I think women talk a lot. For men, if you cry, you are a wimp. Women survive a lot longer because they share whatever is on the table and they get support and ideas from everyone. It is easier for a woman to accept another person's advice.

Changes in Relationships

After the loss, some changes were noticed in relationships with others. Nomusa felt that her brother and sister-in-law were a little "nicer" now that her daughter was dead. More importantly, her relationship with her partner had changed and become more intimate. She said:

> My daughter did bring us together – the partner I have now. At that time, we were just friends. We decided to keep it that way. And then after she passed away, then we decided to take it a bit more serious and make it something.

Prudence also experienced a deepening in her relationship with the father of her baby that died. She said: “It has brought me closer to my partner because I think he understands what I went through. So if I talk to him, he understands it better than any other person.”

Unfortunately for Nomzamo and Phumzile, their relationships deteriorated after their loss. Nomzamo reported that she had no friends anymore: “The relationships just broke down over time.” And Phumzile commented:

> I tried to get closer to my mother’s family but I found out that I was rejected cause I was so needy financially…So that’s when I was pushed to living with my boyfriend cause I found out that he was the only person who could love me…I know I cannot on them.

Findings from the Professional Literature

Relatively little is known about the influence of social support on distress among individuals who experience AIDS-related bereavement, and the few available studies have produced inconsistent results (Ingram, Jones, and Smith, 2001). One of the first studies to assess the relationship between social support and grief reaction was by Lennon, Martin and Dean (1990) who sampled 180 gay men in New York City who had been bereaved due to AIDS during the first five years of the epidemic (1980-1985). Structured, face-to-face interviews were conducted with these men in mid-1985. Most participants were white, well-educated men in their 30s. Grief reaction was measured through a newly developed 12-item scale: the items of this scale were taken from several existing grief scales. Availability and adequacy of instrumental and emotional support were assessed by questions relating to help and support received with caregiving responsibilities when the partner was sick with AIDS and questions relating to support for emotional pain associated with watching one's partner die of AIDS. Not surprisingly, men who had taken care of their partner during the illness had a more intense grief reaction following the death compared to men who had not been caregivers. Furthermore, participants who had received inadequate help with caregiving responsibilities experienced more intense symptoms of grief after the death compared with those who reported receiving adequate support with caregiving. Similarly, participants who felt that they did not receive adequate emotional support for the pain they experienced while caring for their dying partner also had a more intense grief reaction than those who felt that they had received adequate emotional support. The researchers of this study emphasized that it was not the mere *availability* of instrumental and emotional support that influenced grief reaction but the perceived *adequacy* of the support. With regard to these findings, Gluhoski, Fishman and Perry (1997) suggested that they be treated with caution because participants were reporting on support they received five years earlier and their recall may have been distorted.

Ingram, Jones and Smith (2001) assessed the role of social support and unsupportive social interactions in depression among men and women experiencing multiple AIDS-related loss. They studied 90 bereaved individuals, most of whom were gay, lesbian or bisexual. Most participants were white and college-educated, and most were HIV-negative. The researchers measured unsupportive or upsetting responses that participants received concerning their bereavement by means of the 24-item Unsupportive Social Interactions Inventory (USII). The Social Support Questionnaire was used to measure the amount of support available and participants' satisfaction with it. High levels of unsupportive social interactions during bereavement were significantly associated with increased depression. The two types of unsupportive social interactions that led to increased depression were "distancing" (behavioral or emotional disengagement from the bereaved individual) and "bumbling" (behaviors that are awkward, uncomfortable, intrusive and focus on "fixing" the bereaved individual). The other major finding was that decreased depression was evident among participants who reported a greater number of people in their support network and who were satisfied with the level of social support. HIV status was not significantly associated either with social support or with depression among the participants of this study. In a report on 86 HIV-positive and 167 HIV-negative participants from the UCSF Coping Project, Rosengard and Folkman (1997) found that HIV-negative caregivers who reported many caregiver burdens and perceived little social support reported the most suicidal ideation. But perception of social support was unrelated to suicidal ideation among HIV-positive caregivers and the reasons for this were unclear.

Gluhoski, Fishman and Perry (1997) assessed the role of social support (and hardiness) in mediating bereavement distress in gay men many of whom had experienced multiple AIDS-related loss. Data were obtained on 589 gay men (42% were HIV-positive and 58% were HIV-negative). The sample consisted mainly of white men who were well educated. The mean age of the sample was 34. Measures were used to examine social support, hardiness, relationship to the deceased, number of losses, depression, and anxiety. The results indicated that participants with high levels of social support were less distressed overall than participants with low levels of social support. However, the researchers pointed out that high amounts of social support did not absolutely protect those who experienced loss, especially when there were high levels of loss. This has been confirmed in other studies. For example, Folkman, Chesney, Collette, Boccellari and Cooke (1996) studied 37 HIV-positive and 73 HIV-negative caregivers participating in the UCSF Coping Project. They analyzed data that had been collected a few months before and after the partner's death. Social support was assessed with 23-items from the Social Support Questionnaire. The main finding was that social support did not predict the course of depressive mood after the partner's death. In their 1995 study of 199 HIV-infected men and women in Wisconsin, Sikkema et al. (2000) measured the influence of social support on grief reaction. The Instrumental Support Evaluation List (ISEL) scale was used to assess the perceived availability of potential social resources. No differences were found in social support for those who experienced AIDS-related grief symptoms and those who did not experience grief symptoms. In a subsequent study done in the late 1990s with a similar sample in Wisconsin as well as New York, Sikkema, Kochman, DiFranceisco, Kelly and Hoffman (2003) again found no significant relationship between social support and severity of grief reaction.

Conclusion

Looking at the various sources of support, ranging from support from the government in terms of medical and welfare services to support from family, friends and neighbours, it was evident that participants had resigned themselves to not expect much of anything. While they wished that there could be more support made available at the macro-level, it was more hurtful that support was so rare at the micro-level. While research conducted in developed countries has shown weak relationships between the availability (and quality) of informal social support and degree of bereavement distress among those who have lost loved ones to AIDS, it is unclear if similar findings would be obtained in the local context, considering that the availability and degree of both formal and informal support services in the local context are so much less. In the chapter that follows, attention is focused on the physical and psychological impact of AIDS-related bereavement.

CHAPTER 12

The Impact of an AIDS-related Death

This chapter discusses the psychological and physical impact of AIDS-related deaths on participants. Special attention is paid to the effects of bereavement on HIV-positive participants since more than two thirds of the sample was HIV-positive. The final section of the chapter deals with the issue of multiple loss.

Bereavement Distress

Differences in Bereavement Distress Based on HIV Status

In the current study, it was difficult to make a distinction between bereavement reactions among participants who were HIV-positive and those who were HIV-negative because the sample was so skewed; only 5 of the 18 participants were HIV-negative. It is beyond the scope of this qualitative investigation to test for significant differences on this issue, so we have to rely on quantitative reports from the US. Certainly, we need to conduct quantitative studies of our own to explore whether there are differences in bereavement distress among HIV-positive and HIV-negative individuals in the South African context.

One of the earliest and most well-known studies of the psychological impact of bereavement associated with AIDS was conducted by Martin (1988). A total of 745 gay men living in New York City were interviewed in 1985 and comparisons were made between men who had experienced the loss of someone close from AIDS and men who had not lost anyone. A total of 198 men in the sample were bereaved by AIDS and a direct association was found between bereavement and traumatic stress response, demoralization, sleep problems, sedative and recreational drug use (e.g. amphetamines, barbiturates, cocaine, and hallucinogens), and more frequent use of psychological services for personal AIDS concerns.

In a subsequent study, Martin and Dean (1993) examined the influence of AIDS-related bereavement on psychological distress among gay men from 1985 through 1991, and participants were divided into two groups: bereaved and non-bereaved, and within each group, they were again divided into HIV-positive and HIV-negative groups. Data were collected once per year in private, face-to-face interviews. The researchers found that the bereaved men scored higher than the non-bereaved men on all measures of distress during the study period, though psychological distress was also high among the non-bereaved men. The group that experienced the greatest effects of bereavement were those who knew they were HIV-infected themselves and were facing the prospect of their own death to AIDS. As the years passed, HIV status became a more relevant predictor of distress than bereavement status. Martin and Dean (1993) noted that the psychological impact of loss was diminishing among these participants. Bereavement that was distressing in previous years was becoming less so over time. The researchers volunteered two main explanations for these findings. First, concerns over one's own health and HIV status could be replacing bereavement as the primary determinant of psychological distress among gay men and second, men who were uninfected or asymptomatic may have become habituated to the experience of losing loved ones to AIDS. It would be interesting to conduct a similar kind of longitudinal study to see whether the same trend has occurred among South Africans.

Folkman et al. (1996) assessed depressive mood in HIV-positive and HIV-negative gay men just before their partner died and up to seven months after the death. The researchers did note high levels of depressive mood among the bereaved caregivers throughout the seven months after the partner's death, but the duration and severity of the depressive mood was comparable with that reported in the literature for bereaved spouses. During the seven months after the death, there was not a marked difference in depressive mood between HIV-positive and HIV-negative bereaved caregivers. No relationship was found between the course of depressive mood and multiple loss, and the researchers asserted that the findings of their study were consistent with those of Martin and Dean (1993).

Rosengard and Folkman (1997) conducted a prospective study that examined suicidal ideation in caregiving partners of men with AIDS in the San Francisco, California area. In the sample, 86 men were HIV-positive and 167 were HIV-negative. During the course of the study, 156 men became bereaved. Participants were followed bi-monthly for two years and they were divided into four groups: HIV-positive bereaved and non-bereaved caregivers and HIV-negative bereaved and non-bereaved caregivers. The researchers reported that bereaved men were more likely to experience suicidal thoughts and feelings than the non-bereaved men. However, HIV-positive bereaved men were no more likely than HIV-negative bereaved men to report suicidal ideation. In the current study, only one participant, Sibusiso (who was HIV-positive) had reported that he had contemplated suicide at one point.

A recent US study examined whether gender differences existed in AIDS-related bereavement among those who were HIV-infected. Summers et al. (2004) studied 93 HIV-infected individuals (62 men and 31 women) in San Diego, California who had lost someone close in the previous 12 months (most deaths were due to AIDS). The sample consisted primarily of white, middle class, educated, asymptomatic people with HIV. Participants were assessed for grief reactions, psychiatric morbidity, mood symptomatology, and suicidality using the Texas Revised Inventory of Grief Revised, Structured Clinical Interview for DSM-111-R, the Hamilton Depression and Anxiety Rating, and the Diagnostic Interview Schedule for Suicide. The findings revealed that AIDS-related bereavement affected female participants in a much more negative way than male participants, similar to what was reported by Sikkema et al. (2000) in their earlier study of HIV-infected individuals in Milwaukee, Wisconsin. The study by Summers et al. (2004) provided evidence of more intensified grief responses, higher prevalence of generalized anxiety disorder, elevated overall depressed and anxious mood symptomatology, and higher prevalence of thoughts and gestures of suicide among bereaved women than bereaved men. The data indicated that bereaved women living with HIV were at increased risk for complicated bereavement compared to men. In the sample, 23% of the women met criteria for unresolved grief compared with 10% of the men. One explanation provided by the authors was that most support services in the US for people with HIV target gay and bisexual men who were first impacted by the disease. Furthermore, women with HIV lack the communal support that gay men with HIV have traditionally provided one another. While it is true that women who are spread out across the US are more likely to feel isolated and disconnected from others also grieving AIDS-related losses, it is incorrect to imply that HIV support services in the US continue to cater only to the needs of gay and bisexual men. In fact, this has not been the case for several years, and I base this comment on my 10 years of professional experience in

AIDS service organizations in the US as well as my familiarity with the network of services available to people with HIV/AIDS. I do agree with the authors, however, that "we are in the early stages of understanding the differential trauma of AIDS-related loss on women living with HIV and its impact on physical and mental well-being" (Summers et al., 2004, pp. 238-239). The important point is that we are already in the third decade of AIDS, yet so little is known about AIDS-related bereavement among women even though this is the fastest growing group affected by HIV/AIDS (Goodkin et al. 1996a). This applies particularly to women in Sub-Saharan Africa who experience higher rates of AIDS-related mortality than men. It is hoped that the current qualitative study in which the majority of participants were female, will serve as an impetus for more research on AIDS-related bereavement among South African women.

Funerals and Sense of Mortality

Two themes emerged among HIV-positive participants: increased distress associated with attending AIDS-related funerals and thoughts about one's own mortality.

Funerals

For most participants, attending funerals for people who died of AIDS was very taxing emotionally, as it made them more aware of their own mortality. As Zanele reported: "It reminds me whenever I attend the funeral service that maybe next time it is going to be me." When I asked participants why they continued to attend funerals even though it was so painful, Nomusa like several others answered that "it's showing respect and being there for the family." "Besides," Zanele said, "one day you want people to go to your own funeral too." Participants felt a sense of obligation to go to a funeral if they knew the person. Nomzamo said that she went "because it's people I know".

Funerals were also hard because they were reminders of loved ones who had died before. Besta said: "As the family members are crying and they are upset…it all comes back and it's very painful." Some participants (Zanele, Nomzamo, and Besta) reported that they had attended approximately 20 plus funerals within the past year. As Mthoko said: "In our location, people know a lot of people and go to a lot of funerals." When asked if she was surprised how many funerals she attended, Doris replied: "No, I am not surprised because so many people have AIDS." For most participants, funerals for people who died of AIDS had become routine. Prudence remarked:

> Every weekend – every Saturday, we have to bury someone...and we know that maybe next week we are going to bury someone else...When someone starts to get sick, we definitely know that is gonna die. Since the HIV/AIDS thing, every weekend, every Saturday, I go to a funeral of a friend, a relative/community member because people are dying like flies out there. It's very difficult knowing that someday it's going to be you, and how about my son?

I asked Doris if so many people would still have come to her brother's funeral if they had known he had AIDS, and she replied: "I still think they would have come to support, but I don't know what they would have been thinking while they were there."

Heightened Awareness of Own Mortality

Some participants had contemplated their own death, either as a result of attending funerals or because of caring for a loved one who was dying. Sizakele commented:

> Physically, you might be powerful...but inside you are finished. Nursing someone, something tells you, you are next! That's one thing that destroys you...It's like someone is telling you...what will happen if I reach this stage? Who will be here for me?

Azon and Nomusa dared not think about their own death. Azon feared dying while Nomusa would not even let the subject enter her consciousness: "Oooohh No. Never. I do not want to even think about it. It is not even in my mind. God cannot take me now. I have not done everything yet. No, not now!"

Most participants, however, indicated that they did not fear death. As Besta remarked: "People die. Nobody is going to live forever. I don't fear death. If it comes, it comes." Sibusiso said: "Death was the one thing I feared but not anymore. One day we will all die regardless of HIV and AIDS....Everybody will die at some time...I don't know when is my time." Zanele said: "So many people have died that I am not scared of it anymore." People don't take notice of it anymore." Prudence drew comfort from her faith and said: "I think the fact that I am a Christian, that is what makes me not fear death because I know that there is another place for Christians...I do not fear death at all."

The only thing that worried some participants was what would happen to their children when they died, and also what would happen in the afterlife. Prudence reported feeling depressed at times:

> When I think about my son usually, and when I think about the fact that someday (it may be soon or later) I am going to die. I am going to get sick very soon. If I know somebody...is in...a very critical position, I tend to see it as if it was myself. I become very depressed.

Sizakele became quite upset imagining what it would be like after she died. She said:

> I don't have so much fear for death but the fear that I have is what will happen after I die? I always close my eyes tight and imagine the soil on top of my body (crying) and the suffocation...as if I will still be feeling that. You know when you think about it, it gives you such a fright...You try to imagine...what is going to happen. You can't get the real answer about it. And the loneliness! That's one thing that bothers me. I try every time to put it away.

When asked if she thought about death a lot, she responded: "Yes, there are certain times...Sometimes...something triggers that feeling....Like at night...that's the time when I normally think so much about it...I will sometimes kneel down and pray or maybe I will just turn on the side."

I asked Sibusiso if there was anything in particular he would want as he lay dying, and he replied:

> Yes, if my family and friends would come and cheer me up…It would be very important to have people who have loved me around. Even though the ones that hate me will come and pretend. But their presence is very important…after all, we are all humans and we all make mistakes and we need to support each other.

Impact of Bereavement on Physical Health

General Bereavement and Physical Health

The death of a loved one is likely to be one of the most stressful life events ever to confront an individual. As Sanders (1993, p. 267) pointed out, "grief affects everyone, but unequally. Some people are severely affected and die; others seemingly take it in their stride, painfully acknowledging the loss but somehow managing to go on with their lives."

There is clear evidence that a significant minority of individuals are susceptible to increased morbidity and mortality following bereavement (Kim & Jacobs, 1993; Stroebe & Stroebe, 1993a). One of the first studies to demonstrate a link between bereavement and immune functioning was by Bartrop, Luckhurst, Lazarus, Kiloh, and Perry (1977). Since then, a number of clinical studies have shown that bereavement can result in a reduction in immune function which might have health consequences (Irwin & Pike, 1993; Biondi & Picardi, 1996). Most of these studies are related to spousal bereavement. For example, in one study 212 older widows and widowers rated their own health two months following the death of their spouse and they were compared with 162 control participants for a comparable period. The bereaved group reported significantly more recently developed or worsened illness, more medication use, and rated their health more poorly overall (Thompson, Breckenridge, Gallagher & Peterson, 1984).

But not all studies have been as clear-cut. For example, Zisook et al. (1994) studied 21 middle-aged widows who had lost their spouses two years before and 21 demographically matched married women. Both groups were evaluated twice over a 13-month period. There were no statistically significant differences on any of the immune measures between the cohort of widows and the control group. However, widows who met the criteria for major depression demonstrated impaired immune function compared to other widows. So, the authors of this study suggested that there could be a relationship between depression and immune function in bereaved individuals.

In their review of cross-sectional and longitudinal studies in developed countries such as the US, United Kingdom, Sweden, Finland, and Israel, Stroebe and Stroebe (1993a) concluded that mortality risk increases for the bereaved. Again, most of these studies were conducted among widows and widowers and few known studies of this type have been conducted in developing countries. The greatest risk for mortality is during the first few weeks and months after the loss of a loved one. The most likely causes of death for the bereaved are suppression of the immune system (infectious diseases), a lack of will to live (suicide), failure to take protect oneself (accidents), or unhealthy lifestyle (heart disease and cirrhosis of the liver). We are still in the process of understanding the complex mechanisms that determine why and how bereavement results in various physiological changes (Stroebe, Hansson & Stroebe, 1993).

From 1964 to 1987, Schaefer, Quesenberry and Wi (1995) followed 12,522 pairs of spouses in Northern California. During this period, 1,453 men (12%) and 3,294 women (26%) were bereaved and of this group 440 men (3%) and 510 women (15%) died during follow-up. The authors found that mortality following bereavement was significantly elevated in men and women after adjusting for age, education, and other predictors of mortality. The highest risks of mortality occurred 7-12 months following bereavement. In a similar study that was conducted in Israel and covered the time period 1983-1992, 9% of men and 27% of women became bereaved and excess mortality among this group was demonstrated (for both men and women), especially during the first six months after the loss of the spouse (Manor & Eisenbach, 2003). The authors found that bereavement had a greater impact on the more educated men. An interesting study was conducted by researchers at Harvard Medical School whereby 30,000 couples where the deceased spouse had used hospice care was compared with an identical size population-based sample (Christakis & Iwashyna, 2003). A small but significant difference in mortality was detected between bereaved spouses whose husband or wife had used hospice care and those bereaved spouses whose husband or wife had not used hospice care. Mortality was slightly lower among the bereaved whose spouses had used hospice care before they died, thus demonstrating a possible beneficial effect of hospice on bereaved survivors.

In their comprehensive review of the literature on the physiological correlates of bereavement, Hall and Irwin (2001) cautioned that while studies have demonstrated alterations in physiological functioning after loss, more refined research is needed to evaluate "causal relationships among measures of physiological functioning, morbidity, and mortality in association with loss" (p. 487).

Physical Impact of AIDS-Related Bereavement: Participant Accounts

Most of the HIV-positive participants had been on a roller coaster ride in terms of their health. They had experienced the full gamut of symptoms associated with HIV disease and most had been hospitalized several times. While trying to remain upbeat, most were aware of how fragile their health was. Even Azon, who was in denial about having the virus, knew that he was very sick. Bathoko had confronted her condition head on and was not optimistic about the future: "I'm expecting everything! I have now been sick for two years. I don't want to think about the future or tomorrow. I don't want to, cause I don't know...I don't know if in two years I will be still alive."

None of the HIV-positive participants was currently receiving ARVs and, in most cases, it was not by choice; they simply did not have access to these drugs. Delarise did not think ARVs were for her because she believed in following the "naturalist" or holistic route. On the other hand, Sibusiso was afraid of taking them because of the side effects and because he feared that he would have difficulty adhering to the treatment plan. For the rest, they were hoping for a miracle.

A common theme among participants (uninfected and infected) was the physical toll of caregiving and grief. Of course, this was a particular concern for participants who were already in fragile health. On the experience of caring for her daughter, Nomusa commented: "Sometimes I think that I might have been the one who passed away because I was sick as well." Sizakele was devastated by the physical toll of caring for her sister-in-law:

> I was available to my sister-in-law in every way. And when I checked my CD4 count, it made me cry, it made me cry. I lost so much – more than

> 200 in about two months time – something I had worked for it…a very long period…and it just got wasted, just like that.

Prudence described the ordeal of seeing her infant son fight for his life:

> That four months of my life was very difficult. I was in and out of the hospital. I didn't take care of myself. I didn't have time to bathe. I didn't have time to eat. I didn't have time for myself. I didn't have time for anybody else. The only thing I was thinking about was my son, and is he going to get well, is he going to die? I didn't care about my status at all…Sometimes I tell my mom that I wish it was me who was lying there not my son.

Ragani, who was HIV-negative, also reported health problems in response to the stress of caring for her young niece and then watching her die:

> Eating was a problem because when I watched the baby not eating a thing, it used to break my heart. It used to kill me every time I sat down for supper or lunch and I looked at Shanni…Actually both my Mum and I couldn't eat for a long time after she died. It took a while before things started getting back to normal. I had sleepless nights and then our family doctor put me on a light dose of valium to sleep.

Physical Impact of AIDS-Related Bereavement: Data from Other Studies

While studies have been conducted to determine the association between psychosocial stressors, immune function, and health outcomes in HIV-infected individuals (Rabkin et al., 1991; Cook et al., 2004; Alciati et al., 2001; Mulder, Antoni, Duivenvoorden, Kauffmann, & Goodkin, 1995; Leserman et al., 2000; Perry, Fishman, Jacobsberg & Frances, 1992), no controlled research has been conducted yet on the impact of bereavement itself on disease progression in HIV-infected individuals. A few years ago, Goodkin et al. (1996a), indicated that "specific studies of the impact of bereavement itself on progression of CDC stage, time to AIDS, and to death are yet to be reported in HIV infection." (p. 209). Several years later, this still appears to be the case (Goodkin et al., 2001). To date most of the research has only focused on the impact of bereavement on <u>immune function</u> (as opposed to disease progression) in HIV-infected individuals. These studies have almost exclusively focused on gay men in the US and yielded inconsistent findings (Goodkin et al. 2001). Three teams of researchers (Rabkin and colleagues at the New York State Psychiatric Institute, Goodkin and colleagues at the University of Miami, and Kemeny and colleagues at the University of California) have been the main investigators in this area.

In a cross-sectional study, Kemeny et al. (1994) assessed immune parameters among 90 gay men, half of whom were bereaved and half of whom were non-bereaved over the previous year. The bereaved group consisted of men who had lost one or more close friends to AIDS during the past year. Individuals who reported the death of a partner were excluded from the study. Contrary to their hypothesis, Kemeny et al. (1994) found that that there was no difference on immune measures between the bereaved and non-bereaved regardless of HIV status. Furthermore, the number of close friends who had died over the previous year and the length of time since the most recent loss was not associated with immune parameters among both bereaved uninfected and HIV-infected men. The only difference that was found was for HIV-infected men who were not bereaved but who were depressed. Immune changes for this group included a decreased CD 4 cell count. Kemeny et al. attempted to explain the finding that repeated bereavement was not associated with immune changes by suggesting, like Martin & Dean (1993) that repeated bereavement allows some individuals to adapt psychologically, thus reducing the potential for physiological or immune consequences. They recommended that studies be done to confirm whether depressed mood contributes to a decline in CD 4 cells but they cautioned that it was important for studies to discriminate between grief and depression and to use separate measures for the two.

However, in a subsequent report Kemeny et al. (1995) did find a relationship between bereavement and changes in the immune system among HIV-infected gay men. Unlike the previous study, this longitudinal study included men who had lost an intimate partner.

A sample of 78 gay men from the Los Angeles area was studied (36 uninfected and 42 HIV-infected). A total of 39 participants had lost an intimate partner to AIDS during the previous 13 months. In addition to a battery of psychological measures, two blood samples were obtained from each bereaved participant – one drawn on average 10 months before the death of the partner and one drawn within 13 months after the death of the partner. Two samples were obtained from each non-bereaved participant over an equivalent time period. Participants were excluded if they had AIDS or were taking antiviral medications (e.g. zidovudine). Similar to their previous study, Kemeny et al. (1995) found that non-bereaved HIV-infected men who were depressed had significantly fewer CD 4 cells. But in contrast to their previous study, they found that bereaved HIV-infected men did show changes on immune measures (though no differences on CD 4 cell count) compared to non-bereaved HIV-infected men. There were no differences in immune changes over time between uninfected bereaved and bereaved men, however. The authors of this study explained that immune changes occurred in bereaved HIV-infected men because the death of a partner is a more profound experience for men who are themselves infected. Overall, the results of this study supported the hypothesis that the death of a partner is associated with changes in the immune system that *could* affect the course of HIV-related disease.

The challenge of separating the contributions of grief reactions and depression to the immune system among those bereaved by AIDS continued to be a theme in another study by Kemeny and Dean (1995). They investigated the relationship between AIDS-related bereavement and subsequent changes in CD 4 cell levels and health over a 3-4 year follow-up period among 85 HIV-infected gay men (29 of whom were bereaved) in New York City. Interview data was collected each year to assess psychological, behavioral, and health factors, and blood samples were drawn yearly to assess CD 4 cell levels. Bereaved men showed a significantly greater loss of CD 4 cells over the follow-up period than the non-bereaved men. Regression analyses showed that these differences were not explained by differential use of recreational drugs, exercise, sedatives, antiretroviral drugs, presence or absence of other health behaviors, or the health status of participants when they entered the study. The researchers reported a differential impact of grief reactions on CD 4 cell levels versus depression. Grief reactions were not related to reductions in CD 4 cell levels or symptom onset while depression was predictive of CD 4 cell loss. The researchers indicated that the CD 4 decline could not be attributed to the cumulative number of AIDS losses, thus supporting the notion of diminishing effect of losses as reported by Martin and Dean (1993).

Goodkin et al. (1996b) reported different findings in their study of 79 HIV-infected gay men (30 of whom had lost a close friend or partner to AIDS) participating in a longitudinal study. Participants were assessed twice – 6 months apart – to investigate the associations between bereavement and cellular immune function. Participants were excluded if they were on antiretroviral medications. Immune decrements were found among the bereaved during this period. This study was notable because it was the first study of bereavement and the immune system in which mood states (depression, anxiety, overall distress) and other relevant psychosocial factors (stressful live events, availability of social support, and coping style) were simultaneously controlled for. These psychosocial factors did not account for the effects of the bereavement itself, so it appears that bereavement alone was responsible for the immune decrements. Active coping style was also positively associated with immune functioning confirming their earlier research (see Goodkin et al., 1992b).

Multiple Loss

Because AIDS is so prevalent in South Africa, it is not surprising that most participants experienced multiple AIDS-related deaths among people close to them. There were varied reactions to repeated loss including pain, acceptance and numbness. Sizakele who had lost three siblings as well as 30 other people to AIDS remarked: "One doesn't get used to it. Each and every episode has its own impact." She added that "it was devastating because I depended on most of them…All those you need the most will be taken away and those that you hardly need will always be with you." She was not able to attend every funeral because "once there were two funerals on the same day…at two different places." The constant onslaught of death frightened her: "The world is going to be finished …the way people are dying." Mthoko commented:

> Everyday, someone dies. It is almost like the world is turned upside down…It is horrible, and some of the people that die I used to be close with. And some of the people that die, I didn't see them buried because I was away and I found out when I got home after two to three weeks. It feels horrible.

Participants struggled to make sense of the world around them. Bathoko commented: "Everybody is sick…Every time you are looking at somebody who is not feeling well, who is coughing…everybody is sick and it is hard. Sometimes, three persons in the family: maybe mother, father, and daughter." Zanele was in shock and fearful of the future because "all the kids…are dying of this disease." Similarly, Besta said: "We are really worried and we don't know where to start or where to look. What went wrong? Now the young ones are dying".

Being exposed to so much loss required participants to develop ways to deal with the situation. Besta reported that her family kept on losing members to AIDS "month after month – until we decided it was an ongoing thing. You calculate this one has gone and this one has gone, this one has gone…" She continued:

> We decided that we will never grieve in a way that you will see, like wearing dark clothes. But we grieve in our hearts – just doing it in our hearts – not in a way for other people to see that I lost someone. We don't do it anymore.

Sibusiso had lost nine family members in total to AIDS in total, and when asked how he made sense of it, he responded: "I understand it, because that's how life was meant to be. I accept it because that's the best way to deal with it." Sizakele remarked that people find a way to cope because they have to focus on more pressing issues in the present (like poverty) and this proves to be a distraction. In the past two years, Nomusa had witnessed the death of about 20 members of her support group. Her philosophy was the following: "It is painful to see the person die. But, it gives us more strength for whatever we have to do – because some of them died of careless mistakes and something we can avoid."

Ragani, when asked how she coped with dealing with three successive deaths in her family, remarked:

> You reach a point where you become numb. You just go through the process because you've had enough and you can't take it anymore. And in all honesty, I don't believe in God anymore –I don't....because as far as I am concerned that baby didn't have to suffer like that. If she had to die, let her die in peace. The suffering she went through! I promise you – to watch a little child die like that - is no joke!

In the next section, I examine the professional literature on the subject of multiple AIDS-related loss.

Themes from the Professional Literature on Multiple AIDS-Related Loss

David Nord has written a number of articles including a book on multiple AIDS-related loss (Nord, 1996a, 1996b, 1997; 1998) with the goal of drawing attention to this phenomenon and to help those who are traumatized by the effects of surviving multiple AIDS-related deaths. Intuitively, one would expect that those who are confronted with multiple AIDS-related loss would be more at risk for complicated bereavement than those who report fewer losses. However, research has not clearly demonstrated this (Springer & Lease, 2000). In an early study, Martin (1988) found a relationship between the number of AIDS-related losses gay men in New York City experienced and increased emotional distress. However, this correlation was not confirmed in subsequent studies (Neugebauer et al., 1992; Kemeny & Dean, 1995; Cherney & Verhey, 1996; Folkman et al., 1996).

In an Australian study, Viney, Henry, Walker and Crooks (1991) found that gay men who reported more AIDS losses exhibited higher levels of anxiety (e.g. about death and separation) and anger than those with fewer losses. However, the less bereaved men experienced more depression and guilt. A more recent study was conducted by Ingram, Jones and Smith (2001) with 90 people (mainly gay, HIV-negative men) who had experienced on average 9 AIDS-related losses. Again, no significant relationship was found between number of losses and depression. The researchers suggested that future research should focus less on the number of losses and more on "the individual's subjective experience of present grief" (p. 303).

Neugebauer et al. (1992) reported findings from another cohort in New York which supported Martin and Dean (1993). In a sample of 286 gay men (123 HIV-positive and 84 HIV-negative), they examined whether deaths of close friends and partners from AIDS increased the frequency of depressive symptoms and depressive disorder in participants. They also examined whether these losses influenced thoughts and feelings in a way that denoted preoccupation and searching for the deceased. The researchers found that a greater number of AIDS losses was associated with increased preoccupation with and searching for the deceased. However, neither the number of depressive symptoms, demoralization scores, nor diagnosis of a major depressive disorder was related to the number of AIDS-related losses reported. These findings applied equally to both HIV-infected and uninfected participants and there were no differences in the impact of loss based on the type of relationship with the deceased (e.g. close friend, partner, former partner).

Neugebauer et al. (1992) suggested that the social, political, and cultural mobilization of the gay community had provided protection against complicated grief reactions in response to multiple loss. They indicated that "the gay community has developed coping mechanisms to assist members in dealing with multiple losses" (p. 1378). Goodkin et al. (1996a) offered two additional explanations for these findings. First, these men may have become more accepting of so many deaths at a young age. Second, the more subdued reaction consisting of numbing, avoidance, and feelings of detachment may be interpreted as symptoms of post traumatic stress and not a reduction in reaction to loss.

Summers et al. (1995) studied 286 gay men (222 were HIV-positive and 64 were HIV-negative) between 1989 and 1993 in San Diego, California and found that 60% of the men reported a loss within the previous 12 months, and 43% of this group reported multiple losses in the preceding 12 months. The researchers found that 18% of the bereaved men met criteria for unresolved grief. Men with unresolved grief were three times more likely to suffer from a current psychiatric disorder when compared to resolved grievers. A high prevalence of major depression and panic disorder was evident in men with unresolved grief. It is interesting to note that multiple loss was equally common in men with resolved grief and unresolved grief. Kelly et al. (1996) offered the following comments on this study: the study did not assess the impact of HIV status on grief resolution; it was unclear whether depression and anxiety disorders contributed to unresolved grief or the converse; and it was difficult to define the criteria for the resolution of grief.

Sikkema and colleagues from the Medical College of Wisconsin have conducted several studies in recent years to address the paucity of information about AIDS-related bereavement among minorities and HIV-infected heterosexual men and women in the US. One study was conducted just before the introduction of ARV treatment in the US and involved a cross-sectional study of 199 HIV-infected individuals who were recruited in 1995 in Milwaukee, Wisconsin (Sikkema et al., 2000). The sample was diverse in terms of gender (84% were males and 16% were females); race (59% were black, 32% were white, 4% were Hispanic, and 5% were of other ethnicities); and sexual orientation (65% were gay or bisexual and 35% were heterosexual). A large majority of participants (80%) had experienced AIDS-related bereavement, and two-thirds of those who had experienced an AIDS-related loss reported grief symptoms in the past month. The mean time since a loss or multiple losses was 10 months. The average level of grief reaction as measured by the Grief Reaction Index was similar to that found in earlier research on AIDS-related bereavement among gay men in New York City in the 1990s (Lennon, Martin & Dean, 1990). Bereaved participants exhibited elevated scores on measures of psychological distress including depressive symptoms, general psychiatric symptomatology and traumatic stress. Participants who were white and gay or bisexual men were more likely to report grief symptoms; however grief reaction was more severe among women and those with more HIV-related illness symptoms.

Sikkema, Kochman, DiFranceisco, Kelly and Hoffman (2003) conducted a subsequent cross-sectional study in 1997-1998 (in the era of ARV treatment) with 268 HIV-infected men and women in Milwaukee, Wisconsin and New York. Participants reported knowing on average 30 close friends and loved ones who had died of AIDS. Even though the average time since the primary loss occurred was more than three years ago, high levels of grief reaction continued to be exhibited (similar scores to their previous study). The researchers attributed this to the combination of living with HIV and experiencing multiple losses. Participants exhibited mild depression and traumatic stress overall. Predictors of grief reaction included loss of someone close to AIDS, history of injection drug use, and depressive symptoms. Unlike their previous findings, Sikkema et al. (2003) found grief reaction in this study to be more severe among non-white participants, furthermore there were no significant differences for grief based on gender or sexual orientation.

In one of the few studies done in the US in recent years exclusively on AIDS-related bereavement among women, Ickovics, Druley, Morrill, Grigorenko and Rodin (1998) who surveyed 168 women from urban public health clinics in New Haven, Connecticut, found that women who experienced multiple AIDS-related losses over the course of the study were significantly more anxious than those who experienced no loss or just one loss. There was no relationship between number of AIDS-related losses and depression however, thus indicating some form of adaptation (healthy or unhealthy) to loss as reported in prior studies of gay men (Neugebauer et al., 1992; Martin & Dean, 1993; Kemeny et al., 1994). Ickovics et al. (1998) concluded their report with a few comments that pertain to the US context but are equally relevant to the South African context. They noted that there was a need to focus attention on both individuals and communities impacted by multiple losses and to identify "individual and social resources that protect against the deleterious impact of loss" (p. 11).

Findings from Qualitative Research

Several qualitative studies have examined the phenomenon of multiple AIDS-related loss within the gay community in the US. Biller and Rice (1990) conducted interviews with seven participants (five gay men and two lesbian females) from Long Beach, California. With the exception of one participant who had AIDS, all the participants were HIV-negative or had not been tested. The researchers concluded that coping with multiple AIDS deaths was very difficult for participants. Participants were never able to resolve their feelings about previous losses because they were confronted with new losses. At the same time, they failed to grieve the most recent losses because they were focused on earlier, more significant losses. It is interesting that in the current study only one participant mentioned this factor.

Multiple, ongoing loss was identified as a theme in a qualitative study of the bereavement experiences of 16 gay men in London and Surrey (Wright & Coyle, 1996). Twelve of the 16 participants had experienced three or more AIDS deaths in the past five years. Multiple AIDS-related bereavement as experienced by these participants, was reported to have largely negative consequences. Participants reported that new losses were reminders of previous losses and each new death compounded the grief associated with past losses. Some also talked about not having time to recover between the deaths. Mallinson (1999b) explored the experiences of multiple AIDS-related loss among six HIV-negative gay men. These men reported many losses: one participant reported 12 losses among his friends, another reported dozens of deaths, while the other four estimated that they had witnessed more than 200 AIDS-related deaths since the epidemic started. The themes that emerged from the narratives were categorized into two overarching themes: the meaning of multiple loss and the management of the losses. Participants recounted the day-to-day realities resulting from the loss of so many friends. The losses meant the decimation of one's family of choice, a loss of community, loss of a sense of identity, loss of connection with others, and the loss of the natural course of life with friends dying at such an early age. Participants viewed the future with fear and hopelessness. The second theme across the narratives described the challenges inherent in dealing with multiple losses. Participants struggled with internal conflicts and were torn between trying to adapt to ongoing loss and finding a way to escape from the situation. Mallinson (1999b) noted that "the degree of emotional numbness and normalization of death detected in these men was extraordinary" (p. 28). He indicated that the results of this study supported the assertion that coping with multiple AIDS-related deaths was overwhelming and placed individuals at risk for bereavement overload. Like the other qualitative studies on multiple AIDS-related loss, the results of this study need to be interpreted with caution not only because of the small sample size but also because the experiences of white, well-educated gay men may not be representative of other communities also affected by AIDS. But they do offer further evidence of psychic numbing in response to multiple loss.

Need to Address Multiple AIDS-Related Loss

Despite the fact that many individuals grieving multiple AIDS-related deaths do not exhibit overt reactions indicative of greater psychological distress, researchers warn that those who are assisting individuals bereaved by AIDS should still be alert to other symptoms that could be interpreted as complicated grief reactions (Nord, 1997). Several authors have suggested that many of these bereaved individuals may be suffering from a form of trauma similar to post traumatic stress syndrome (Bigelow & Hollinger, 1996; Goodkin et al., 1996a; Nord, 1997). Based on their work counseling people with AIDS at a San Francisco hospice, Bigelow & Hollinger (1996) indicated that one of the ways their clients coped with "unbearable" loss was by numbing. They explained:

> Numbing refers to our ability to turn off our emotions, to avoid painful thoughts and images, to deny the full impact of our grief. It may feel like depression, going through the motions, wooden, moving under water, feeling distant from people and events. This capacity allows us to process the pain in small doses, to reduce our anxiety while we gradually come to terms with the reality of losing so many loved ones so quickly. However, all of us who have used this skill for a long time know that feeling numb is very far from feeling good. In fact, it can lead to hopelessness, fatigue, and suicidal feelings. (pp. 89-90)

Nord (1997) devoted a chapter in his book to understanding multiple AIDS-related loss within the framework of traumatization. In addition to psychic numbing, individuals experiencing multiple AIDS-related loss may also show signs of withdrawal from activities, relationships with others and plans for the future. There is a pulling back from life and these individuals may feel "What's the point?" Nord (1997) argued that current diagnostic criteria are inadequate for assessing trauma associated with multiple AIDS-related loss and he proposed a new trauma syndrome for people experiencing ongoing traumatization as opposed to post traumatic stress – *multiple AIDS-related loss syndrome.* According to Nord (1997), "it is time to recognize the traumatic effect of multiple AIDS-related loss and begin the process of developing effective intervention strategies" (p. 157).

Conclusion

The fact that 13 of the 18 participants in this study were HIV-positive and in compromised health made it important for me to find out what effect the loss of a loved one to AIDS (as well as multiple loss) had on them both emotionally and physically. While U.S. studies have not demonstrated consistently that bereaved HIV-positive individuals will experience greater psychological distress or negative effects to their immune system than HIV-negative individuals, providers need to be aware that HIV-positive clients in the local context who are bereaved may be more vulnerable because they are exposed to a great deal more stress than those in developed countries. In the current study, participants who were HIV-positive reported being taxed, physically and emotionally, from either caring for their loved one or from experiencing repeated loss. Some participants had experienced staggering losses to AIDS and reactions to so much loss ranged from heightened personal death anxiety to numbness. We need to learn about the long-term impact of multiple loss among individuals, especially women, in the local context. Now that we have covered the impact of AIDS-related loss on participants, the next chapter deals with how they coped.

CHAPTER 13

Coping

In Chapter Three, I described various theoretical explanations of how people cope with grief and bereavement in general. Now, in this chapter, I document the actual coping responses of participants who lost loved ones to AIDS-related deaths and relate it to findings reported in the professional literature.

Most people who experience the loss of a loved one are able to cope with bereavement without major long-term physical and mental health consequences, and only a small portion of the bereaved suffer serious consequences that require assistance from professionals (Parkes, 2001; Bonanno et al., 2002). But individuals who are bereaved due to AIDS confront additional burdens (e.g., stigma, lack of social support, being HIV-infected, poverty) which place them at increased risk for complicated grief as discussed in the previous chapters. With so many people bereaved on account of AIDS in South Africa, it is important that we try to understand how they cope psychologically with their loss.

Again, most of the research on coping with AIDS-related loss has been conducted in the North American context with samples of gay men. Because there is virtually no research on how people cope with AIDS-related loss in Sub-Saharan Africa, the best we can do is review the available research evidence from the US. Susan Folkman and her colleagues have produced the largest number of publications in this area and they have used the cognitive theory of stress and coping as the framework for the bulk of their research. Thus, most of our understanding about how people cope with AIDS-related bereavement is derived from this theoretical perspective.

It is important to briefly mention the source of the data used by Folkman and her team. Most of their published reports stem from data collected by the University of California, San Francisco (UCSF) Coping Project, a longitudinal study of caregiving and bereavement among 314 gay partners of men with AIDS from the San Francisco area. Participants in the project included both HIV-positive and HIV-negative gay men coping with caregiving and bereavement. Most of the reports published by Folkman and her group are based on data collected from 1990 until 1994 approximately. Some later reports are based on data that were collected up until 1997 when the project was concluded. Both quantitative and qualitative data were collected. Face-to-face interviews were conducted with participants every 2 months for 2 years, then every 6 months for an additional three years. Physical exams were conducted every 6 months throughout the study (Folkman, 1997a). Different reports focus on different periods of time before and after the partner's death, but most reports tend to focus on data collected approximately two weeks before the partner died and then 2 and 4 weeks after the death and then again one year later. To date, the UCSF Coping Project has been the most comprehensive source of longitudinal data on how gay men have coped with AIDS-related loss in the U.S. context.

The unique aspect of the UCSF Coping Project was that comparisons were made between various groups of gay men: HIV-positive caregivers, HIV-negative caregivers, HIV-positive bereaved caregivers, HIV-negative bereaved caregivers, and HIV-positive men in primary relationships with healthy partners (non-caregiver group) (Folkman, 1997a). The main limitation of this project however, was that its findings were specific to a cohort of gay men in San Francisco. Participants were mainly well-educated, white men in their 30s and 40s living in an area with the largest gay population in the US. As a result, it is difficult to generalize these findings to other groups bereaved by AIDS in the US (e.g. minorities, women) as well as those bereaved by AIDS elsewhere in the world. Another caveat is that the UCSF Coping Project excluded individuals who had more than two symptoms of HIV disease, were diagnosed with AIDS, or used injection drugs. This severely limits one's ability to apply findings to individuals with more advanced HIV disease or AIDS who are coping with bereavement. Needless to say, these individuals make up a substantial portion of those grieving AIDS-related losses, especially in developing countries.

Repressive Coping

A dominant means of coping for participants in the current study was to suppress their emotions, and this was mainly in response to the perceived lack of social support (formal and informal) and the daily struggle to survive. It was also a way to avoid dealing with the pain of the loss. Nomusa reported:

> I think we tend to ignore it and we tend to not want to talk about it because we know it's going to bring back those kind of emotional memories. We don't want to talk about it because it is going to be emotional –so we don't want to do it at all. I am finally trying to forget even though I do not want to. I am trying to get used to the fact that she is no longer there, because whenever I think about it, it tends to be an emotional state for me. I cannot explain how I want to deal with it, but somehow I am trying to forget. I am trying to make peace with the fact that she is no longer here. Ja.

When asked if she talked to anyone about her grief, she replied: "No. I do not believe in doing that. I feel that it would just cause more pain for me." This sentiment resonated with almost all participants. Azon said: "I prefer to deal by myself. I want to keep it to myself. I just say one day I will be okay." But Ragani countered: "It takes a lot of control!"

Tuli remarked: "Crying is a sign of weakness. For everybody- it is a sign of weakness." When I asked her how the interview was going, she responded: "It's getting closer to the truth and I don't like it. It opened up old wounds." She explained that being in control of her emotions was very important to her as a way "to fend for myself." When asked if she was surprised that she still had so much pain, she started crying: "Ja, because I thought I was over it....When I came here, I knew what I was going to tell you but now..."

Parts of the interviews proved to be difficult, though cathartic, for most participants. Zanele remarked:

> After talking to you, it brought back some very painful memories for me. It wasn't a bad thing – it's just I miss her (sister) even more. It was the first time in a long time that I have spoken to someone about it.

Most participants reported that they felt "somehow relieved" by talking about their experiences. Nomusa commented: "Being in this interview has helped me a lot…I realize that it helped me somehow because when I talk about it I am somehow relieved…and I could see that I did not have as much tears as I usually have." And Bathoko said: "I feel this is something that has taken away from my two shoulders."

This "new" experience had made several participants realize the value of sharing their emotions:

> Phumzile: I never had a chance to talk about things that have been kept in my heart and in my mind. So it was for me a certain kind of breakthrough…to be really able to express what was inside me. It was good for me.
>
> Nomusa: After having done it, you realize that you need to. Ja. It helps to talk.
>
> Prudence: For me, talking about me losing my son helps. It helps a lot rather than to keep it to myself. Just laying it out helps a lot. If people only knew how important talking is. To me, talking is more important than keeping it to myself.
>
> Besta: I shared this for the first time – all this grief. I will tell the people it makes you feel better to talk about it.

In their meetings with me, participants had the opportunity to share their feelings and experiences in a safe and non-judgmental atmosphere, and it demonstrated to me not so much the importance of "working through" one's grief but rather the value of receiving support and comfort from others. I came to the conclusion that participants' tendency to avoid dealing with their emotions or talking about it to others was a reasonable response considering the context in which they lived, and it saddened me that they had so few opportunities to receive kindness and support from others.

Bonnano (2004) has been quite critical of bereavement theorists who insist that grief is something that must be worked through and who maintain that individuals who do not show pronounced grief reactions following loss are probably suffering from pathological grief in the form of absent grief. Bonanno has conducted several studies among the bereaved and demonstrated that "emotional suppression" can be adaptive in the context of bereavement. In studies of bereaved spouses, Bonanno, Keltner, Holen, and Horowitz (1995) found that "repressive copers" (those who rated themselves low on negative emotion - avoiding unpleasant, thoughts, emotions, and memories) had minimal grief symptoms at 14 months after the loss compared to spouses who were not "repressive copers." In a follow-up study, those high in emotional suppression in the first months after the loss did not experience adjustment difficulties two years later (Bonanno & Kaltman, 1999).

However, it is interesting that studies of people bereaved by AIDS have shown that cognitive escape/avoidance is associated with negative bereavement outcome. In a three year follow-up report of 86 bereaved participants from the UCSF Coping Project, Moskowitz, Folkman, and Acree (2003) indicated that participants who were more likely to use cognitive escape/avoidance o (e.g., "I had fantasies or wishes about how things might turn out") immediately after the death took longer to reach recovery from depressive mood. This relationship between escape-avoidance and negative mood among those bereaved by AIDS is consistent with other studies (Moskowtiz, Folkman, Collette & Vittinghoff, 1996; Rosengard & Folkman, 1997; Sikkema et al., 2000; Sikkema et al., 2003; Ingram, Jones and Smith, 2001).

The coping strategy of "distancing" may be related to what Bonanno refers to as "emotional suppression" (Moskowitz, Folkman & Acree, 2003). In their report, Moskowitz, Folkman, and Acree found that participants who used distancing (e.g., "I went on as if nothing had happened") at one month post-bereavement had a stronger likelihood of achieving a positive state of mind quicker over the three year study period. However, different results have been found for the effect of distancing on depressive mood among individuals bereaved by AIDS. An earlier report by Moskowitz et al. (1996) on participants from the UCSF Coping Project showed no effect of distancing on positive or negative mood 3 and 5 months after the loss. Similarly, Folkman et al. (1996)

reported that the use of distancing before the death of a partner did not relieve depressive mood seven months following the death. Distancing did not predict depressive mood 3 years post-bereavement either (Moskowitz, Folkman, & Acree, 2003). Sikkema et al. (2003) reported no significant relationship between the use of distancing and severity of grief reaction. In fact, Ingram, Jones and Smith (2001) found that greater use of distancing actually increased depression.

On the other hand, ruminative coping - defined as worrying excessively and passively about one's distress (Nolen-Hoeksema, 1991) - is not helpful either. Using data from UCSF Coping Project Nolen-Hoeksema, McBride and Larson (1997) analyzed and explored the relationship between rumination and self-analysis on the one hand and psychological distress among gay men bereaved by AIDS. "Rumination" was described as having regrets about caring for a partner (e.g. not having done enough, things that he should or should not have said), feeling negative emotions, concerns that he was isolating himself to focus on himself, and concerns that he was not adjusting well to the loss. "Self-analysis" reflected the participant's attempts to understand the loss and his reaction to the loss. Nolen-Hoeksema, McBride and Larson concluded that it may be maladaptive to think either too much or too little about a trauma including one's reactions to it. This sounds intuitively right.

Balancing Engagement/Detachment

Carmack (1992) conducted in-depth interviews with 19 participants (16 gay men and 3 lesbian women) in San Francisco to identify the processes they used to deal with multiple AIDS-related deaths. All participants were white and college-educated and their mean age was 43 years. Theoretical sampling was used to select participants with varied experiences in degree and extent of AIDS losses. What emerged from the interview data was that participants attempted to cope with multiple losses by attempting to maintain a balance between functional engagement and functional detachment. The researchers suggested that those who were able to juggle functional engagement and functional detachment coped more effectively with multiple losses than those who could not maintain a balance. Participants reported constantly moving back and forth along a continuum between functional engagement, dysfunctional engagement, functional detachment and dysfunctional detachment. Functional engagement was achieved when participants engaged in activities that supported others and made them feel that they made a difference. Dysfunctional engagement occurred when participants felt over-extended and burned out in helping others. Functional detachment was achieved by finding ways to protect oneself from emotional pain and not becoming over-involved. Going away for the weekend, and meditating were examples of functional detachment. With regard to dysfunctional detachment, this occurred when participants felt numb, out of touch and helpless.

Finding Meaning

The literature is replete with examples of humankind's search for meaning as a way of coping with suffering and loss, the most notable being Victor Frankl's book, *Man's Search for Meaning* (1963), about his experience as a Holocaust survivor. Several studies have investigated the phenomenon of searching for and positive meaning in one's loss amongst people bereaved by AIDS. In their study of participants from the UCSF Coping Project who were bereaved by AIDS, Folkman (1997a) asserted that a common theme underlying coping strategies associated with positive psychological states was "searching for and finding positive meaning" (p. 1215). In another report, Folkman et al. (1996) indicated that finding positive meaning in caring for a loved one dying of AIDS resulted in less depressive mood during the months after the death of the partner. Thus, they suggested it may be wise to help caregivers of people with AIDS to consider the positive meaning of their caregiving (e.g. the sense of their competence as a caregiver, the comfort and satisfaction that comes with knowing that one provided important practical and emotional support during a person's last days).

Bower, Kemeny, Taylor and Fahey (1998) also investigated the discovery of meaning among 40 HIV-positive gay men who had recently lost a close friend or partner to AIDS. These men were recruited from the Multicenter AIDS Cohort Study. Looking at death certificates of participants over a 4-9 year follow-up period, the researchers found that 15 of the 40 participants in this study died of AIDS, and only 3 of these men indicated that they had found meaning from the death of their close friend or partner. On the other hand, 13 of the 25 survivors did report finding meaning from the loss. Thus, the researchers concluded that the lower rate of AIDS-related mortality among participants who found meaning from their loss may be attributed to a less rapid decline in CD 4 cell count. Of course, a direct causal relationship between discovery of meaning and subsequent AIDS-related mortality could not be established because this was not an experimental study.

Writing in the early 1990s when the death toll from AIDS was extremely high in the gay community in the US, Schwartzberg (1992) proposed that a central need among those grieving deaths and coping with the impact of AIDS was to "find some meaning or sense in AIDS" (p. 427). Subsequently, Schwartzberg (1993) conducted a qualitative study of 19 HIV-positive gay men to find out if they found meaning in, or made sense of AIDS, and what strategies they used to do so. Overall, he found that most of the men attempted to create meaning from both having HIV disease as well as having lost so many people in their social network. Both positive and negative meaning was ascribed to the impact of HIV/AIDS on their lives. Ten major themes emerged from the interviews about the way HIV was viewed (in descending order of frequency mentioned by participants): as a catalyst for personal growth, it provided a sense of belonging to a community, it was a source of irreparable loss, it was a punishment, it contaminated or stigmatized a sense of one's self, it was a strategy to receive love and attention, it was a catalyst for spiritual growth, it caused isolation from the rest of the world, it confirmed one's powerlessness, and it provided relief (e.g. enabled men to disclose their sexual orientation).

In the current study, five main themes emerged among participants in terms of the way they had come to view their loss. The death of a loved one to AIDS was perceived as fate; it reinforced the uncertainty of life; it was a source of personal growth; it was a catalyst for helping others; and it reinforced the place of spirituality in their lives.

Fate

For a number of participants, there was a sense of resignation and acceptance concerning AIDS and the loss of their loved one to the disease. Only a few questioned why their loved one had died of AIDS or why South Africa was so affected by the disease compared to many other countries in the world. Mthoko said he had wondered about this but "the answer I did not get it". He added: "The only thing that can help is helping the community because it will help erase bad memories or thinking about it." Felicity also got no answers: "I say 'Lord, why did she die?' And then I won't get the answer." Prudence reported that she had difficulty understanding why babies were also victims: "because I feel babies are very innocent and they deserve better."

Many participants were adamant that no-one deserved AIDS and that it affected everyone equally. Bathoko commented: "It doesn't happen to a group of people for a reason. We are all the same." Nomusa admitted that she had questioned why she had lost her child to AIDS: "But then I say 'who else would it have been?' He knew…that I would be a strong person to handle it." Prudence added: "Many people have to understand…that it doesn't mean…that we are an evil person if you already infected with HIV and AIDS... Even if you are HIV-positive, it doesn't mean that God is punishing you at all. It doesn't mean that at all."

On the whole, participants were not angry but rather accepted that loss was a part of life. Here are some statements that illustrate this point:

> Sizakele: It's not only AIDS that makes people die. There are many other diseases that kill people…It is beyond our understanding how one will pass away…It is just a point of accepting and just live positively with it because once it's there you cannot change it.
>
> Bathoko: I have learnt that you must expect everything, and hope. We have to face life. I am trying to put aside the worries"
>
> Felicity: You have to accept. I have to say to myself, no matter how hard, I have to deal with it.
>
> Sibusiso: If a person passes away, he passes away. We'll meet again in the future.

Uncertainty of Life

Participants' view of life around them had changed as a result of their loss as well as becoming infected (for some of them). Besta remarked: "Ten years ago, it was much better. AIDS was not in our premises or in our families. But now, it is within us. Now it is frightening."

The world was no longer regarded as a safe place. Sizakele reported: "There is so much unsafeness, uncertainty." Participants realized now no-one was immune to the epidemic. Tuli said: "Now I know that HIV can shock anyone – anytime. It doesn't choose. In fact, if you are having a boyfriend, chances are that he has AIDS." Felicity who was HIV-negative felt much more vulnerable:

> I used to think its only young people who contracted AIDS. Now even old women, anyone, can get HIV...It has made me more aware of things around...There are so many sicknesses around...Even my children – I make sure that I really protect and I teach them: don't run to other children when they hurting. There is blood. Don't touch it!

Several participants attempted to gain a sense of mastery over the unpredictability of life by focusing on the importance of getting tested. For example, Mthoko said: "I understand that people out there need to know to take care of themselves....It is very important to look after their family and to look after themselves so they don't spread AIDS." Others coped by believing that one should be prepared to expect anything. As Nomusa said, "I am very much aware to expect anything at anytime." Similarly, Prudence remarked:

> I have learned anything can happen in life. I always have to leave a space for disappointment in life. Today I can have a job and the next day I can wake up not having a job. This day I can have my Mom and the next day I can wake up and she is gone. I have learned to leave a space for disappointment.

Personal Growth

Some participants tried to view their loss in a positive light and indicated that it had given them the opportunity to learn more about themselves as well as those around them. Prudence reported:

> HIV and AIDS – it's bad, but it has teached me a lot about life. I'm not saying I am justifying HIV and AIDS but if it's already there, you have to deal with it in a positive way. Be positive.... Dealing with the loss of someone is very difficult; it's not a good thing. But you grow –you grow sometimes in a harder way.

Delarise believed that being HIV-positive was "a blessing". She explained:

> It has given me a purpose. It has given me a passion. My passion and purpose is to go out and make a difference. As much as it has ravaged and raped the world, I think it has done a lot of good. We are talking. We are talking about subjects we didn't talk about previously, and even to some extent, it is bringing communities together. It is bringing families together, it is forging new relationships. It is forging friendships. So I look at the positives of HIV..."

What participants learned as a result of their loss differed from person to person. Prudence was less afraid now and she was also more appreciative. She said:

> Besides harmful things, I do not fear. I try to take life as it is. In my life, I have lost the most important thing...now I do not fear anything. I just take life as it is. The only thing that I fear is what if my mom passes away. That is the only fear I have. I am grateful for my new job. I am grateful for my son. I am grateful for my family. I am grateful for my support group. I am grateful for almost everything. I have grown a lot. Sometimes you have to learn it in a hard way.

Doris also expressed more appreciation for her family. She said: "I am grateful for my family. My big family is incredible to me....I have a very warm family. I have a good relationship with my sisters-in-law."

Several participants reported that they felt stronger and more capable to deal with life's challenges. Phumzile remarked: "It has made me believe I can take just about anything. You can go through just about anything because whatever happens in my life, I will say it's just a phase. I will go through this and I will be fine again." Similarly, Nkosi said: "I am very strong now...I have responsibility...I have learned a lot and I see there is nothing I cannot do. Life teaches you what you can do."

The experience had made Nomusa and Sibusiso wiser. After the loss of her daughter, Nomusa said: "I think it made me much older because I can see the pain." And Sibusiso commented:

> I think the younger generation is stubborn; they don't give you a positive thought. They just want to have fun. Older people discuss situations and matters. I can ask someone older than me for advice. I feel closer to people who are wiser and more mature...I think I am growing up. My mind is in another stage now.

The loss of her brother, sister-in-law and niece had taught Ragani about responsibility. She reported:

> I think if my brother had been a bit more responsible...and if he had been faithful to his wife, this would not have happened. It has made some dramatic changes in my life. I basically had to take on a ready-made family. It wasn't like having a baby and bringing it up. It was just like I was "BANG" in the middle of it and I just had to cope. So it does have its negative sides. I'm not going to deny it because it's not the carefree life. If I want to go out somewhere at night, I have to worry about the kids and make sure they're okay."

While there might have been some personal growth for Ragani, the losses seemed to impact on her in profound and perhaps irreversible ways, with loss of faith in sex, marriage and family as can be seen by the following:

> It has made me a much stronger person...It has taught me a whole lot and being more family oriented....I made a decision: no marriage, no children for me! I can't deal with it. I cannot see myself having children. After the loss of Shanni, it's a bit much....I've been in a relationship with somebody for 13 years. We had initially wanted to marry...It has affected the relationship in a sense that I can't share the same closeness...I'm scared of losing him. I'm scared of the whole HIV thing, seeing people die in front of me. And always believing that my brother was such a faithful person; I never knew that he was unfaithful to his wife...I do not wish to have a child. To me, that was my baby.

Mthoko learned how his family had pulled together after his brother died:

> It has caused so much emotional grief. But I have seen that there is so much love...the way we look after and taking care of one another...That we belong together – that is what I have realized...I have seen other families that aren't so close.

Desire to Help Others

Their loss experience had inspired several participants to help others who were similarly affected by the epidemic. Nomusa was more sensitive about the needs of people affected by HIV/AIDS in her community. She said: "I want to help other people...People who are nice to me – that's what stays in my mind. In my surrounding area, I make it a point every day when I come back home to check on people." Ragani reported: "I have actually become more involved in the Department of Social Welfare in Phoenix. I advise people who are taking care of a sick person at home." Prudence said: "I have realized that

I can do something to help other women not to lose their babies like I did and to help people who are living with HIV/AIDS understand their disease..."

Becoming HIV-positive as well as losing a loved one to AIDS had motivated Sibusiso and Delarise to focus all their energies on HIV prevention work in their community. Sibusiso remarked:

> I want to help...and say that living with HIV/AIDS is not the end of life. I want to share my story with someone different from my background. I want to make sure, whatever chance I get, I share my story with someone else. If I do something good for others, then I feel happy about it.

Delarise echoed this by saying: "I am here to provide another face and another race to this disease and I am here to provide each one of you with hope and that I'm living proof of someone living with HIV and certainly not dying." But she feared she would not be able to reach out to enough people. She explained: "Sometimes I'm sitting and not doing anything in the evening and I think I could be doing something. I should be meeting people...and educate them..."

Spirituality

The majority of participants relied on their faith both as a way to understand their loss experience as well as to draw strength and comfort from it as they coped with life without their loved one. There was a tendency to believe that everything was in God's hands and that he knew what was best. Mthoko remarked: "You are taught everything happens for a reason." Nomusa said: "Before, I used to blame him. But I think I have come to terms with it. I am starting to understand that he knows who is going to be brave enough to handle it when the time comes." Phumzile agreed: "I think through it all God knows what's there for me. And I think he's planning better things for me." Prudence reported:

> My Mom always tells me...when you go through a rough patch in your life, God is usually up to something, and I believe that everything happens for a reason. I must not accuse God of doing anything wrong because he

> is a planner. He is everything. He knows exactly what he is doing. As a Christian, I know that God has a purpose beyond all this – all this pain that I had to go through.

Bathoko captured the feeling of many participants when she said that God was "all I have." Tuli said: "I have learnt from my bible to cast all my burdens to him." And Doris said: "When I got to my church, I was healed." Mthoko commented that he relied on his faith "because some of the stuff I couldn't handle myself." And Sizakele said: "Everything that is happening in my life is for a reason, as far as God is concerned. There are maybe things that he is strengthening me for...It's just faith that I've got in my God that's kept me going."

A number of participants used the word "strength" when talking about their faith. Nomusa indicated that church was a big part of her life: "That is where I get my strength. It is very much important to me." Nkosi said that it was through prayer that he was able to get through each day: "Praying is a very, very important thing in my life." Prudence said the same thing: "The main person I talk to is God. I have learned how to pray a lot. I get relief when I pray.... I prayed and I prayed and I can assure you that praying heals, spiritually." It is interesting that several participants reported going to church regularly and drawing enormous comfort from their faith, however they could not trust any of the other church members or church leaders by sharing the nature of their loss. Nomzamo was able to tell her deacon about the loss of her two sisters to AIDS and the fact that she also was HIV-positive. He apparently said that he was glad that she told him but he also expressed concern that maybe she should not be telling everyone in the church because not everyone would be understanding.

Several participants commented that they could not be angry with God and believed that he did not wish for them to have regrets. But there were a few who were not as enamoured of religion. Sibusiso who was Catholic said:

> Sometimes I believe in the bible and sometimes I don't...I used to go to church but due to the stigma and discrimination from the church members,

> I decided to stay home and pray....When I disclosed to the members last year, everybody was shocked and some even talked behind my back.

Ragani reported that she was totally turned off religion: "Oh, absolutely! But the sad thing is that, because of me, the girls are totally off religion. I know it's not good because every individual is supposed to have this thing about religion."

Studies on Spirituality among Individuals Bereaved by AIDS

Turning to the professional literature, Richards and Folkman (1997) described the association between spirituality and coping, mood, and physical health during the first month following bereavement among 125 gay men from the UCSF Coping Project. Data were obtained from physical and mental health assessments as well as narratives that were elicited from the participants about events surrounding the death of their partner. Their report analyzed quantitative data and qualitative data from open-ended interviews conducted within a month after the death of the partner. More than one half of the bereaved participants made explicit references to spiritual phenomena in their narratives. It was evident in their discussion of spiritual beliefs, experiences, and rituals that participants adopted a spiritual perspective to help the dying partner deal with approaching death. They also helped the bereaved partners accept the reality of the death. Forty-three percent of these participants believed that their relationship with the deceased continued but in a different form. This spiritual perspective was considered to be a primary source of emotional support for these participants, helping them create positive meaning during a time of intense grief. Participants who expressed spiritual beliefs also used more adaptive coping (positive reappraisal, planful problem solving, and confrontive coping) versus escape-avoidance coping. However, an important finding was that having a spiritual perspective was also associated with increased depressive mood and anxiety. Furthermore, HIV-positive participants were no more likely than HIV-negative participants to talk about spiritual phenomena.

A follow-up study was conducted with the same cohort 3-4 years after the loss of the partner (Richards, Acree & Folkman, 1999). Data was obtained from 70 of the original 125 participants. Similar measures were used to collect data. There was an increase in how many participants now spoke about spirituality (77% versus 54% in the first study), and an ongoing relationship with the deceased partner was reported by 70% of the participants. Unlike the first study, no statistically significant relationships were found between spirituality and mood and coping, nor was there a relationship with physical health symptoms. The researchers noted that the use of spirituality as a means of coping declined as time passed and now it functioned as a means of personal growth, providing direction and meaning to participants' lives.

Continuing Bonds with the Deceased

Few participants appeared to be actively engaged in sustaining symbolic ties with the deceased. Some participants occasionally shared stories of the deceased with others. Some described vivid dreams they had of the deceased.

Keeping Memories Alive

Nomusa said this about her nine year old daughter who died: "There are times when it happens that we end up talking about her. But I am glad that we never cry about it when we talk about it." She recalled that her fondest memory was of her daughter playing cards: "We would switch off the TV and just play cards. It used to be like a tournament...She used to beat me and I would be so angry. I taught her to play cards and she beat me (laughs)." Prudence who also lost a child said:

> You know, what I remember about my son is that he was not a crying baby. He usually laughs although I saw he felt some pain. But when he laughs, I was very happy, and that is what kept me going – that at least he is laughing.

Doris said: "One thing I learned was to cherish all of the memories that you have." She still wore her wedding ring. "I still wear it," she said, "because I still love my husband." Most participants reported doing things like going to the cemetery on anniversaries and keeping photos around of the deceased. "We think of them, we talk about them and we look at the photo albums," said Sibusiso. "They are all happy memories." Prudence said she visited the cemetery every year on her son's birthday: "It is very difficult but I have to do it anyway." She added: "We talk about him a lot. We even have a photo of him in my house – a big framed photo...You know, it helps, it helps us to heal. Yeah...a picture around...He is a part of us. Yeah." Nomzamo also reported going to the cemetery once a year on the anniversary of her sisters' deaths. On the other hand, Delarise remembered her best friend by visiting her friend's mother on her birthday: "I am not a graveyard person!"

Besta said that Christians usually did things like pray all night and light candles to remember the deceased. And Ragani reported: "We do something on the yearly death day of the person. We do a little prayer. We call the priest and in the Hindu culture, it is called "Havan". You light a fire and there is chanting." Tuli indicated that she did not do things like lighting candles or visiting the cemetery to remember her deceased sister: "No. Because we are saved, so we don't have to do those things. The only thing we have is the photo...It's in the past. Let her rest in peace."

Dreams

Several participants talked about having vivid dreams of the deceased. Some of these dreams appeared to represent the participants' struggle to come to terms with the death, some were traumatic, and some were comforting. Sibusiso reported that he had a dream about his brother the week before:

> I dreamt about him sleeping in the same bed. I ask myself, 'This person is dead now. How come he's sleeping next to me in my dream?' I wake up at that moment and he was gone. Yesterday, I told my aunt that I dreamt about him. She said that's because you miss him and he's missing you too. In our culture, if a person comes and shows his back, then it's bad luck but if he's with you and is sleeping with you, then something great is going to happen."

Doris reported that she had several dreams about her husband: "I see him alive but I know he is dead. In the dream, I can't understand how he is alive." Prudence had dreams of her infant son who died at four months of age: "Sometimes I dream about him playing with his brother, sitting at home with all of us...Every time when I dream about him, he is four months old."

Disturbing dreams were reported by a few participants. Ragani remembered a dream that involved her deceased brother and deceased niece:

> I had a dream just about six months after Shanni died. I am having a great big fight with my brother. He came home in my dream and he's taking Shanni with him and he tells me, 'I'm taking her home.' And I tell him you can't take her – she's mine. I tell him, you gave her to me, you can't take her now. He looks straight at me and says, 'Rags, she never was yours. She's mine and I'm taking her.' And in my dream, I'm ready to hit him, and then he says, 'What's wrong with you?' I always talk about that dream. I suppose it was an awakening that she was really not my child.

A week or so after the funeral of her daughter, Nomusa had a dream: "She was like turning in the coffin and she was crying for me – calling for me" (starts to cry). Mthoko said: "I used to have nightmares and I used to see my brother through the dreams and I remember he used to say that I must take care of myself, that I am not dead yet."

Few participants reported pleasant dreams of their loved one. Azon had a dream about his deceased ex-wife: "I was dreaming about staying together in the old house when we were together. It was a good dream. I was sitting with my young daughter and my wife kept on walking past us."

Future Orientation and Goals

When asked what they saw in their future, most participants reported that they hoped to be better off financially, which was understandable considering their current dire economic circumstances. Tuli said: "I just want to be comfortable. A car and a house, that's all - and a good paying job." Monica had the same wish: "I dream a lot of things: a house, car, money." Mthoko hoped that in three years time he would be living by himself and be self-supporting.

Furthering one's education and getting a job were top priorities. In five years time, Sizakele said:

> I am having hope of getting employment and I have never gave up on studying…The second thing…is to get a place for my children and I pray that God won't let me die before I see to it that my children have a shelter.

Ragani indicated that she hoped to complete her studies and she said: "I hope to see the kids get on with their lives…I see the future as rosy…because I see the potential in the children and they are really going to make good lives for themselves." For Zanele, her wish was "to have a big nice house and to live happily with my kids - and a better job too."

Azon remarked: "My job doesn't pay much money…I want to open something up for myself –VCR repair shop because it's busy all the time and I can make a lot of money." Prudence was hopeful for the future:

> Sometimes I see myself having a bright future with this ARVs. I think I still have a future. I still have enough years to raise my son…I want to go register for some courses at the University of South Africa. I am going to get married later this year. That is the bright future I have.

Some participants expressed great optimism for the future. Phumzile declared: "I believe this year is going to be a turn around year for my life," "My life is going to be better. I want to go to school part-time…it's never too late to go to school. I can still graduate." Doris exclaimed: "I see a very bright future. Just like Oprah said, 'my future is so bright I can't even see anything!'" Her goal for next year? "A big farm, a beautiful car, a youth project, enough money to make me comfortable and get a doctorate."

Clearly, the goals for many participants were quite grandiose. But it was these dreams and hope for a better life in the future that kept them going each day. When asked where she saw herself in three years, Felicity responded: "I see myself as a millionaire. I see myself as a prosperous person, making sure that I do everything carefully." Both

Sibusiso and Delarise saw themselves becoming famous for their HIV/AIDS work. Sibusiso reported: "I once told my mother that one day, I'll be a star. One day, I'll be a legend of HIV/AIDS by disclosing." And Delarise said:

> I want to make some kind of movie of my life and I have to get a book published. I believe I've got a story to tell and I need to tell it and I need to provide another perspective of the journey of an HIV-positive person definitely.

Prudence reported that in the next year she wanted "to look back and see how much I have achieved...to see how many people I have managed to help, to see that my centre that I dream about is being built." She continued:

> You still have life to live. That is why many people...do not want to go get an HIV test. They think it will be the end of the world for them. I will never sit around and fold my hands and wait for the day I die. What if I still have 10 years?

Surprisingly few participants talked about their health when asked about the future. Some like Azon and Nomusa said that they hoped to be feeling much better. A few others were not optimistic about their health. Besta reported that she didn't see anything for the future "because everyone dies and everyone is sick." She added:

> It might happen that I might be dead...I don't imagine myself alive at that time...I'm just looking at how people pass so easy....Everybody will die and for my children and grandchildren - how will that be when I'm not here? I am worried about the future because they are all going.

Bathoko remarked: "I have a short plan...two years is a long time...because my life is not that good now...I am so weak." For the next year or so, Nomzamo said: "I just hope I'll still be alive."

In the professional literature, there is evidence of a positive relationship between the way bereaved individuals appraise things (assessments about people, places, events, internal states, actions, and outcomes), setting goals, and having hope for the future on the one hand and psychological well-being on the other. Stein, Folkman, Trabasso and Richards (1997) studied a sample of 30 gay men at the time of bereavement and 12 months later. They reported that participants who appraised events more positively tended to be more future oriented and were able to develop realistic goals and plans with respect to getting on with their lives. Setting long-term goals was associated with improved psychological well-being 12 months later. On the other hand, participants who had focused more on short-term goals and plans for their partner than long-term plans for themselves did less well psychologically 12 months later. Satterfield, Folkman, and Acree (2002) suggested that clinical interventions focus on encouraging hopefulness in the face of high stress by helping bereaved individuals view events differently and mobilizing more effective coping responses.

Reed, Kemeny, Taylor and Visscher (1999) examined data on 72 HIV-positive gay men from Los Angeles who were recruited from a longitudinal study known as the Multicultural AIDS Cohort Study. Participants were given various physical and psychosocial assessments for 2-3 years. The researchers found that positive expectations about future health, feelings of confidence and optimism, and a greater sense of control over one's health were linked to a slower rate of disease progression among bereaved gay men who were HIV-positive. Participants who had recently lost a partner of close friend to AIDS and who had negative expectations about their future health were more likely to develop symptoms over the follow-up period than bereaved men who did not have negative expectancies, after controlling for immunological status, antiviral medication, high-risk sexual behavior, substance use, and depression.

Having Unsafe Sex as a Way of Coping

Losing a loved one to AIDS may heighten risk-taking behavior among the bereaved (Villa & Demmer, 2005). Several participants admitted to engaging in unsafe sex (e.g., vaginal sex without a condom) during the period after their loss and they could not explain why they did this. Not much research has been done on this issue but data from a study by Mayne, Acree, Chesney, and Folkman (1998) of 100 gay men in San Francisco revealed that increased sexual risk taking may occur after the death of a loved one to AIDS. The researchers followed these men for one year before and one year after the death of a partner to AIDS and found that they were at increased risk for unprotected anal intercourse (UAI): at 4 to 6 months for HIV-negative men and at 8 to 12 months for HIV-positive men. The incidence of UAI increased among HIV-negative men from 2-5% before the partner's death to 14% at 4 and 6 months after the death, and then returned to the pre-bereavement levels at 8-12 months. Receptive oral sex to ejaculation also increased at 4 months post-bereavement. Among the HIV-positive men, 11-20% engaged in UAI before the death of the partner and then it dropped to 4-7% during the 6 months after the death. However, UAI then steadily increased to 31% at 12 months after the death. Thus, the period of greatest risk was at 4-6 months for HIV-negative men and at 8-12 months for HIV-positive men. Sociodemographic variables, use of recreational drugs, drinking, depression, and social support did not explain this risk sexual behavior. The authors concluded that risk varies over time based on HIV status and also that risk behavior was more likely to occur when men entered into new relationships. The implication of this study is that individuals (i.e., gay men) bereaved by AIDS who quickly move into new relationships may engage in high risk sexual behavior (unprotected anal intercourse and receptive oral sex to ejaculation), and this behavior does not necessarily occur immediately after bereavement but could emerge many months later. The authors acknowledged that the findings were limited by the small sample and the nature of the sample, so the results could not be generalizable to other gay men living outside urban areas, those with lower incomes, and men of color. Considering these preliminary findings, it is indeed surprising that no follow-up studies have been done in the US or elsewhere.

Resilience

When considering all the stresses that participants endured in their lives in a context dominated by multiple loss, lack of support, ostracism, and poverty, one wonders how they and many others like them in South Africa are able to survive. I have documented the most common coping strategies of participants in this study in response to their loss but I would be remiss in not broaching the subject of resilience. Bonanno (2004) defined resilience to loss and trauma as:

> ...the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, such as the death of a close relation or a violent or life-threatening situation, to maintain relatively stable, healthy levels of psychological and physical functioning. (p. 20)

Over the years, AIDS devastated the gay community in the US but the evidence also suggests that most bereaved gay men were able to weather these traumatic losses (Martin & Dean, 1993; Schwartzberg, 1993; Goldblum & Erickson, 1999). It is remarkable that there have been few studies to date that have specifically examined the notion of resilience among individuals bereaved by AIDS. Park and Folkman (1997) in their report on 53 HIV-positive and 88 HIV-negative bereaved participants from the UCSF Coping Project indicated that participants' psychosocial resources in the form of optimism, religious beliefs and perceptions of social support were "fairly robust" (p. 440) and remained stable over the course of caregiving and bereavement. It is essential that more comprehensive research be done in the future that specifically explores the notion of resilience among people who survive multiple AIDS-related loss in the midst of extreme poverty and a host of other stresses such as in the case of South Africa.

Conclusion

Either unconsciously or consciously, participants typically contained their emotions in response to their loss, which was understandable considering the context in which they lived. In the face of scarce support of any kind and the struggle to survive, participants kept their grief to themselves and tried not to dwell on it. Usually, all they could rely on was their religion and they drew on it for strength and comfort as well as to help them make sense of their loss (as well as their own HIV status). Their religion or faith provided a lens to view the world around them and to assist them in dealing with the challenges and hardships they encountered. In contrast to studies in developed countries, participants did not appear to maintain symbolic relationships with the deceased. This was not surprising considering that they were trying to "forget" about their grief and focus their energies on daily living. A major weakness of studies in developed countries is that few have paid adequate attention to understanding social, cultural, economic and political factors and how they influence coping among individuals bereaved by AIDS, and this is a crucial area for future research, particularly in countries like South Africa where these factors are likely to play a dominant role in how individuals respond to and cope with loss. In the next chapter, we turn our attention to a sample of providers in NGOs in and around Durban to obtain their input on clients' experiences with AIDS-related bereavement and efforts of NGOs in this area.

CHAPTER 14

Provider Perspectives

This chapter describes the experiences of a small group of professionals (mainly social workers) in five diverse NGOs in KwaZulu-Natal that serve people affected by HIV/AIDS. My purpose in interviewing these key informants was not only to bounce ideas and hunches off them to inform my interviews with participants from the primary sample, but also to explore informants' own feelings, experiences and activities related to AIDS-related bereavement. I was fully aware that whatever information I gathered should not be considered representative of the experiences of all professionals and NGOs serving people affected by the epidemic in KwaZulu-Natal, and the reader is reminded of this when going through the analysis that follows.

Background of Key Informants

All key informants were female and were employed full-time, though one informant worked part-time in several locations (semi-private hospitals and an in-patient AIDS facility). The headquarters of informants' organizations were located in Durban, Hillcrest, and Pinetown. Several of them had satellite offices in various areas of KwaZulu-Natal including Umlazi, Chatsworth, Marianhill and Umhlanga. Informants reported that their respective organizations served people throughout the province.

The job titles of informants were as follows: Senior Social Worker, Chief Social Worker, Social Worker, Bereavement Counselor/Social Worker, AIDS Coordinator, Agency Director, Agency Director/Nurse, Consultant/Counseling Psychologist. All positions were full-time except for the counseling psychologist who worked as a consultant in several locations.

The majority of clients served were Black and six of the eight informants reported that they spoke Zulu. With the exception of one informant, all of them had three or more years' professional experience working exclusively with people affected by HIV/AIDS (see Table 14.1).

Table 14.1 Demographic characteristics of informants (n = 8)

	N
Gender	
Female	8
Ethnicity	
Black	3
Indian	1
White	4
Education	
Nursing diploma	1
BA (Humanities)	1
4 year Bachelor/Honours (Social Work)	5
Masters (Counseling Psychology)	1
Years working directly in HIV/AIDS Care	
0-2	1
3-5	4
> 6	3
Place of employment	
NGO	6
Semi-private hospital	1
Multiple locations	1

Profiles of NGOs

During my interviews with key informants, I was able to visit five organizations in Durban, Hillcrest, and Pinetown that served people affected by HIV/AIDS throughout KwaZulu-Natal. In Durban, I interviewed two informants from the HIV/AIDS department of an NGO that served children as well as an informant from a HIV/AIDS support program at a semi-private hospital. In Pinetown, I met with three informants from a NGO that specialized in counseling services for people affected by HIV/AIDS. In Pinetown, I also visited an in-patient hospice facility for people with AIDS and spoke with the informant there. Finally, I interviewed an informant from an NGO in Hillcrest that specialized in home-based care and economic empowerment projects for people with HIV/AIDS.

In addition to being given a tour of each organization, I was able to meet with various staff persons (including lay counselors and volunteers) and clients within each organization, so I was able to obtain a reasonable sense of the mission of each organization, staffing patterns and resources, and nature of services offered. This information enhanced my understanding of the capacity of these organizations to address AIDS-related bereavement as well as their interest in this issue.

It is not my intention to provide a detailed description of each organization I visited, neither is it necessary. Rather, I have provided a snapshot of each organization so that the reader has some idea of the nature of each informant's organization, their clientele and general services offered (see Table 14.2). These serve as a point of reference when reviewing informants' experiences and perspectives.

Table 14.2 Profiles of Organizations

	#1	# 2	# 3	# 4	# 5
Type	NGO	NGO	240-bed NGO nursing facility	NGO	Hospital-based HIV/AIDS Support Program
Headquarters	Durban	Hillcrest	Pinetown	Pinetown	Durban
Purpose	child protection and related services (child abuse, children affected/infected with HIV/AIDS, willful neglect, abandoned children, orphaned children).	Education, counseling, financial support, and income generation projects for people affected by HIV/AIDS.	Primarily medical care for chronically ill and terminally ill HIV/AIDS patients.	Core function is to provide counseling and support, particularly related to HIV/AIDS, rape and domestic violence.	Range of services for people with HIV/AIDS including medical care, social work services and economic empowerment.
Areas served	Durban and surrounding region (from Umlazi to Umhlanga).	Metropolitan area of Durban and Molweni, Embo, Kwa Nyuswa, and Shongweni.	Metropolitan area of Durban and other areas in KZN.	People come from throughout KZN.	Durban metropolitan area and surrounding areas
Staff	approximately 70 social workers (including an HIV/AIDS team consisting of an AIDS coordinator, bereavement counselor and two development/outreach workers).	Director is a nurse, 5-6 part-time nurses, several full and part-time employees who supervise income generation projects, four lay counselors, and 52 home-based workers.	A total of 65 staff including a medical director, nurses, one social worker, two HIV counselors, one spiritual care director (full-time), and one consultant counseling psychologist (employed for only four hours per week).	Twenty staff members including the director, three social workers, two part-time psychologists, administrative personnel as well as a number of student interns (medical students, social work and psychology students).	Mixture of 5 full and part-time medical doctors connected with the hospital, two social workers, one pastoral counselor, one part-time psychologist, 4 lay counselors, various administrative personnel and a few student social workers.

Services	Providing a range of social work services including recruitment and supervision of foster and adoptive parents, residential care (children's homes and community family homes), investigating cases of neglect, abuse, abandonment and orphanhood, individual counseling and support groups, outreach. *Specific AIDS-related services*: Transition planning, foster care for children with HIV/AIDS and those affected by HIV/AIDS, individual and group support services, grief and bereavement counseling (to a limited extent) for children and parents.	HIV/AIDS education and outreach, HIV/AIDS courses offered in Zulu, home-base care, voluntary counseling and testing, feeding scheme, income generation craft project, horticulture project, funeral fund, and school fee fund.	Mainly medical and palliative care for end stage patients.	Includes crisis intervention, individual counseling, support groups, shelters, training of lay counselors.	The psychosocial component of the program (started in 1999) consists mainly of support groups. Individual counseling is also available.

Comments	Largest NGO in KZN, established in 1919, huge caseloads (about 60% of cases involve children affected or infected with HIV/AIDS), 300-400 new foster care applications per month, very high staff turnover. A new position for a bereavement counselor was created one year ago and a person was recently hired. She is in the process setting up bereavement support groups for children affected by HIV/AIDS. A memory box project was established in 2003 and is ongoing.	One of the oldest church-based AIDS organizations in KZN (established in 1991). No social worker or psychologist. Lay counselors have matric-level education and have completed an HIV/AIDS course. Counseling services consist mainly of pre and post test counseling and crisis counseling over the telephone (average 700-800 sessions/phone calls in a three-month period). No grief counseling services.	A "step-down-care" facility which functions as an intermediary between hospital and home-based care. Only such facility in KZN. Established in 2002. Support services are bare bones. Very little psychological support offered to patients, families. Spiritual care provided by a pastor.	Founded in 1997, it is the largest provider of general counseling services in KZN. Served over 15000 individuals face to face so far. Focus on trauma and crisis counseling and community empowerment through a lay counseling training program and training to help individuals set up crisis centers in their own communities. No bereavement support groups per se but grief and bereavement is addressed to a certain extent within other types of support groups and in individual counseling.	Well known program that is affiliated with a semi-private hospital that serves mainly HIV/AIDS patients. Interlinked with a HIV/AIDS research and network group from a local university. About 500 individuals are active participants in weekly support groups. Groups have specific purposes (e.g., photography group, newsletter project, literacy project, men and women's groups). Recently initiated a 4-day training (with 30 clients) on how to do a memory box and discussed issues related to death and dying. Memorial services for support group members who have died.

Poverty Overshadows Grief

As was the case with participants from the primary sample, the dominant theme throughout my interviews with informants was the issue of poverty. Informants were confronted on a daily basis with countless clients living in desperate poverty. One informant said:

> I work with a group whose constituents are very poor, very poor people. Almost all of them are unemployed and most of them are struggling with getting something to eat and waking up every morning making sure there's food on the table...Ninety percent of them are women and they are taking care of the family and eighty percent of them have children.

AIDS was reported to be the "real undercurrent to all the social problems." And the poverty situation seemed to be worsening as a result of the epidemic. As one informant explained:

> In the past, people used to rely on others for support and if they had two pieces of bread, they would share it. But now so many people are dying, and because of the cost of maintaining a family member who is sick, they don't even have a piece of bread to share.

Although all informants recognized the importance of addressing issues relating to grief and bereavement, they felt that in their clients' lives it took a back seat to the more urgent need to eat. An informant said: "They do not have time to deal with the emotional needs. The pressing need is hunger, another mouth to feed." They felt that it was difficult for most people to understand the depth of poverty experienced by their clients, and one informant remarked, "poverty is just a word...I don't know what it is like to live like that and I can't even begin to understand what it is like."

One informant commented that it was a custom when you visit a family that they will want to give you something, usually food or tea. Because her clients were so poor and had no food to offer, they did something else. She explained:

> The most humbling thing is when you go in and they sweep the path in front of you because they can't give you anything to drink or anything to eat...They want to do something for you and they got no food to give to you and so they sweep the path or they have swept the path because they know you are coming and you can see that is done because I know to look for it now. It is about tuning the radio into what people do. It is just like tuning a radio. Someone else could walk down there and not notice it... so I always comment about how nice and clean the place is because that makes their day.

Informants reported that out of desperation people sometimes resort to fraud. One informant had heard from members in her support group that some HIV-negative individuals were trying to pass as being HIV-positive (by using other people's blood, forging documents etc) so they could get a disability grant. Another informant who worked with children reported that fraud and corruption was commonplace in certain areas. Mothers sometimes pretended to be the grandmother and would report that the children's mother was dead, or the "granny" would come and pretend that her daughter was dead, in order to qualify for foster care grants.

A big concern was the length of time it took to receive a government grant. An informant said that the average wait (being optimistic) before an individual received a foster grant, for example, was six months. But there were many cases of clients waiting for up to a year. In the meantime, these people were caring for several children without a job or any government assistance. In situations where a child was HIV-positive, workers tried to expedite the process but it was not uncommon for the child to die before the money arrived. One informant said: "People are poverty stricken and they don't want to listen to your words. They want food. They want a hand out immediately. Their tummies are crying and that kind of thing. And unfortunately, we are unable to assist them."

Three of the five organizations I visited tried to offer some type of emotional support for clients relating to loss, either through group work, individual counseling (to a limited extent) or memorial services. However, their priority was most often to respond to the survival needs of clients. Because grants are out of reach for many impoverished people, the organizations I visited had implemented income generation projects. Only two of the organizations did not have such a project but it was because one was a child welfare organization and the other one was a nursing facility. Informants stressed the importance of trying to link emotional/social support services with skill building (e.g., literacy, lay counseling, HIV/AIDS educator training, home-based care) and income generation activities (e.g., beadwork, horticulture). Each organization attempted in varying degrees to train and sometimes employ members from the community, either as HIV/AIDS educators/ counselors, home-based workers, lay counselors, or community motivators. The goal was to train individuals to go back into their community and to use their skills to uplift the community and also to give them skills that would make them employable.

Caring for the Dying

Informants confirmed that often family members did not know their loved one had AIDS or even that he or she was dying. One informant noted that more people were coming to her organization (which was not a nursing facility) when they were actively dying. She said: "Because of the lack of places for these people to go, they are being brought here and they are dying within days of seeing them." Another informant gave an example of a family who called her and told her that they had been waiting for six hours for an ambulance to take their loved one to a hospital. Her organization was able to arrange for a private ambulance but when she called the family back they told her not bother as they were afraid that transporting their loved one would kill her. Since she was now near death, they decided to keep her at home. The same informant remembered another occasion when family members drove their loved one to her organization and when she walked out to the car, she discovered that the person had just died. Often, it was a worker who was the last one to be with the person "and to hold their hand."

Informants also confirmed that it was almost always women who cared for the sick. As one informant remarked:

> Every time you visit somebody in the community, there is usually a woman sitting by the bedside. This is Africa and women are expected to care whether they like it or not...women are expected to do the caring within the community.

What was alarming was the increase in the number of children who were being expected to care for sick parents. One informant noted: "We get children as young as five years having to care for parents who are sick and they don't go to school."

Home-based care was considered an effective means to help families care for the sick and dying. However, one informant remarked:

> There are some situations where home-based doesn't work such as in situations where so many people have died within the family and there is now only one breadwinner and that breadwinner sometimes has to give up work to care for the sick person. Other times, you will find the sick person being inadequately cared for because they are left on their own all day while the breadwinner goes out to work.

To address this problem, one organization had plans to develop a respite program in the future and had already obtained space in a local hospital (part of a ward) for it.

A final issue that informants brought up was the ambivalence a lot of female clients felt having to care for husbands who had cheated on them and then returned home with AIDS expecting to be cared for by their wives. This was a common theme in support groups conducted by informants. Women described the pain of being thrust into this situation. And typically, they were forced to shift their feelings aside and concentrate on finding a way to care for their terminally ill husband while having little or no resources.

AIDS-Related Bereavement

Holding Back

All informants commented on how difficult it was to get clients to share their feelings about loss, and several reasons were offered for this. One explanation was that the culture (e.g., Zulu culture) is such that people are not encouraged to talk about their feelings. An informant commented that when someone cries it is uncomfortable for people and it is typical to "interrupt" the person and say things like, "Oh, don't cry' or 'Don't worry, everything is gonna be fine.' Some people may believe that you can will yourself to die, and so it is not good to get depressed. So people try not to focus on things that will upset and depress them. As a result of this tendency to suppress emotions, an informant noted that "you will see people still crying over the loss of loved ones after three years." Furthermore:

> As one person is dying…there is also another person dying. So they don't get over one…In some families, so many people are dying – what's happening is that instead of people grieving they are worrying about how they are going to bury this person.

The issue of multiple loss was noted by informants but they seemed unsure how to address it (or even whether to address it). An informant commented: "We have such a high mortality rate. Today, people are crying over this one, and they grieving over this one the next day, and on and on…..So it's a lot of grief".

Another observation was that children were usually kept in the dark about what was going on in the family, in terms of who was sick and even about who had died. Children's feelings were rarely explored. Often, they were not even told that their parent had died. An informant said: "They are told a mother or father disappears…So the mother just doesn't come back, the father just doesn't come back." In their study of HIV-infected adolescents and parents in the North-West Province of South Africa, Strydom and Raath (2005) reported on the difficulty some parents had in telling their children about their HIV status. Furthermore, many parents did not realize or denied the severity of their illness.

Informants recognized the importance of helping clients open up to their families before they died. "Otherwise," an informant said, "the families continue to be in denial and they tell the person that he or she will be coming home soon, and this makes the person feel very alone." Strydom and Raath

One informant told of a positive experience recently with a support group member who had lost her husband. She said:

> It was a remarkable story. When we were having a memorial service for this person...everybody was worried that she was going to break down and cry. But she didn't. She just said, 'I am glad he actually prepared me for this time and we talked about his death, and we talked about how the funeral was going to be run, we talked about the future of the kids, who will be handling the sermons that day, the role of the church where the candles gonna be.

It was acknowledged that it was "very hard" for clients (many of whom were HIV-positive) to deal with loss because it raised the issue of their own mortality. As one informant indicated:

> I think it is extremely stressful. When we are having a memorial service, you'll see that some of the people are already crying. I think that they are thinking about their own lives and about their own deaths. I think there's an element of grieving for people before they die.

Informants noted that it was rare for clients to approach them requesting grief counseling, even when it was listed in the pamphlets as a service offered by the organization. An informant commented that "in the African community, it's very rare for somebody who has lost a loved one to go to an outsider and talk about grief - it is very rare." Informants reported that people often felt guilty that they were still grieving after the funeral but they would not seek help. An informant commented: "We never get people coming in asking for grief counseling even though we publicize it."

Two informants reported that they did more grief counseling with white people who had lost a domestic worker than with other types of people. This reticence to talk about loss or to ask for help appeared to stem partly from tradition and as one informant put it, "the other half is let's close this chapter - we have other things to worry about because life is hard."

Another cultural explanation was that individuals did in fact grieve intensely but then it ceased after the funeral. An informant reported:

> What happens is you have the person die and they are taken way. The body then comes back, but before the body can comes back, for 24 hours, a room is prepared in the house and a mat is laid down with a candle and they pray for the 24 hours before the body gets there. Sometimes it is longer, it depends on exactly what religion you are dealing with but traditionally it happens in some way. The body then comes and is brought to the home where it lies and a period of mourning takes place where people from surrounding areas will come and traditionally bring something – money. The body is usually wrapped in white - dressed in white clothes. It can be in a coffin but sometimes it is just on the mat with the candle. The candle is always burning and women sing. Traditionally, women sit there and sing and they grieve and they wail. It is an intense period of mourning. Once the body is buried it is finished. You have had your time of grief. And that is how traditional Zulu people grieve. They have intense periods of mourning…up to the funeral.

This informant added that, in reality, a lot of people continue to mourn after the funeral, but it is not the traditional way. There was consensus among informants about the need to work slowly and carefully with clients who were having problems adjusting to a loss. One informant indicated that she relied heavily on her "natural empathy". She said: "You can't use your high tech psychological skills that you've been taught elsewhere…I feel that if I can sit with any patient long enough, eventually I will get through to that patient...Eventually they will learn to trust you."

Addressing AIDS-Related Bereavement

The common view among informants was that more could be done to help people express their feelings both before and after the death of a loved one. But informants felt hampered by the constraints posed by culture, poverty and scarce organizational resources. As an informant noted, “In most organizations, their resources are over stretched…they can only deal with bigger problems. Grief and bereavement are not big issues.” One informant remarked that if we were a different society with more resources, the situation would be very different. One organization I visited did not have any social workers or psychologists on staff and the informant reported: “It is beyond our budget. We need a social worker and a psychologist - there is no doubt about it. We just keep trying to keep our heads above water all the time.” Funding from the government was obviously not nearly enough to run any of these organizations and they all depended heavily on private fund-raising.

But even when bereavement support was available, clients were not always receptive to it and this caused some frustration and confusion among informants. An informant remarked: “I don’t know where the answer to it is. We can try counseling people more often but it is almost like once somebody is buried they don’t want any more counseling.”

Support Groups

Although no specific bereavement support groups were being conducted in any of the five organizations I visited, informants indicated that issues relating to loss and grief did come up within other types of support groups that were being run by their organizations. Bereavement support groups were being planned by the newly hired Bereavement Counselor at an organization specializing in child welfare. It was anticipated that each group would run for one week (one hour a day) during the school holidays. The groups would be psycho-educational in nature. Each group would consist of 10 members aged 10-14 years. Individual sessions would be made available to group participants if it was determined they required more specialized attention.

Data on AIDS Bereavement Support Groups

In the professional literature, a lot of attention has focused on the use of support groups for people bereaved by AIDS. However, comparatively little research has been done to assess their effectiveness. The first study done was by Sikkema, Kalichman, Kelly and Koob (1995), who evaluated an eight session AIDS bereavement support group that used a cognitive-behavioral framework. In this US study, eight participants (four men and four women) attended 90-minute weekly group sessions that covered topics related to identifying past and current coping strategies, developing social support mechanisms, and articulating emotional reactions to AIDS-related loss. Participants were taught the difference between problem-focused coping (e.g., changing negative thoughts or expectations, relaxation and imagery strategies) and emotion-focused coping (e.g., stress management, problem-solving, and decision-making). Common concerns and issues for participants of the group included feelings of helplessness and guilt, anger and resentment, mental replay of the partner's death, the difficulties of grieving when being HIV-infected, the impact of multiple losses on developing new social relationships, and insufficient social support. Participants were interviewed separately and administered various measures before the intervention, immediately after the intervention, and three months later. The group intervention resulted in a reduction in overall psychological distress (including depression and grief symptoms such as denial, numbness and preoccupation with the deceased). Furthermore, improved coping was evident at 3-month follow-up. The main limitation of this study was that it used an extremely small, homogenous sample and there was no control group, so the findings have to be viewed with caution.

Goodkin et. al. (1999) conducted a more rigorous study of an AIDS bereavement support group intervention in which 166 gay men (both HIV positive and HIV negative) who had lost a partner or friend in the previous six months were randomly assigned to treatment and control groups. The bereavement support group intervention consisted of 10 weekly 90-minute sessions and combined cognitive-behavioral strategies, social support, and stress management training. Participants were assessed at entry and 10 weeks later when the intervention concluded. Both HIV-positive and HIV-negative men in the bereavement support group experienced reduced overall distress and accelerated grief reduction compared to men in the control group.

Pomeroy and Holleran (2002) assessed a bereavement group with five participants (two mothers whose sons had died of AIDS and three men whose partners had died of AIDS). Participants had lost their loved one within the past two years. This study is notable because the group was designed and facilitated by two social workers (as opposed to psychologists) and because it was psychoeducational in nature. Each session had an educational as well as a support component. The group intervention consisted of six weekly sessions lasting 90 minutes each. The following educational topics were covered: HIV/AIDS and grief, coping with stigmatized grief and HIV/AIDS, unresolved grief and depression, grief, anxiety and social relationship issues, taking care of oneself, and getting support. The support component addressed the following: building trust and self-esteem, coping with grief and challenging irrational thoughts, depression and hopelessness, coping with anxiety and loneliness, meeting one's needs through social support, and the importance of being with others. Participants completed various pretest measures prior to the group starting and posttests at the end of the final session. The authors concluded that the intervention sizably reduced depression and unresolved grief symptoms and it had a moderate effect on anxiety scores.

The most recent evaluation of an AIDS bereavement support group intervention was by Sikkema, Hansen, Kochman, Tate and DiFranceisco (2004) who randomly assigned 235 HIV-infected men and women to a cognitive-behavioural support group intervention (consisting of 12 weekly 90 minutes sessions) or a comparison condition (e.g., individual therapy). To be eligible for the study, participants must have lost a loved one to AIDS within the past two years, and the interesting feature of this study was that it not only involved women but the majority of participants were from minority groups (66% were black or Hispanic). Most of the participants had a history of psychiatric problems such as substance abuse, mood/anxiety disorders, and antisocial or borderline personality disorder). Nearly half the sample had been diagnosed with AIDS and participants reported knowing on average 43 friends and loved ones who had died of AIDS. Assessment measures were conducted at baseline and again 2 weeks after the group intervention. The group intervention addressed the following main themes: developing group cohesion and social support, identifying and expressing emotions related to living with HIV disease and losing loved ones to AIDS, identifying difficulties associated with coping with these losses, identifying stressors and current coping strategies (adaptive and maladaptive), setting goals in relation to coping with HIV and AIDS-related loss, and implementing adaptive coping strategies to reduce psychological distress. The bereavement support group intervention resulted in modest reductions in overall psychiatric distress. Women in the group intervention appeared to benefit more than men, showing greater improvements in grief and depression. The fact that men showed improvements regardless of treatment condition could have meant that grief typically subsides over time even without intervention. Another explanation was that men (as well as women) in the control condition were also offered 12 sessions of individual therapy. A confounding variable that is not elaborated on enough by the researchers is that all participants continued with any psychiatric or psychosocial treatment they had been engaged with before enrolling in this study, so it is not certain what degree of influence this had on improvements. The chief value of this study is that it targeted a diverse group of bereaved, HIV-infected individuals who have been neglected in the literature up to now.

Effect of AIDS Bereavement Support Groups on Physical Health

While there are relatively few studies assessing the impact of bereavement interventions on the psychological well being of individuals grieving an AIDS death, even fewer studies have assessed the impact of these interventions on the physical health of these participants (Goodkin et al., 2001a, 2001b). A few studies have focused on immunological benefits associated with AIDS-related bereavement interventions, and not physical health effects (e.g. clinical disease progression). Goodkin et al. (1998) conducted a randomized, controlled, clinical trial to examine the impact of a semi-structured, 10-week, once weekly, 90-minute session bereavement support group intervention on the immunological, neuroendocrine and clinical health status of participants who were bereaved gay men, compared to a control group. A total of 119 gay men (74 were HIV-infected and 45 were uninfected) were assessed at baseline, 10 weeks, and at six months follow-up. At the six month follow-up assessment, significant immunological changes (changes in CD 4 cell count and total lymphocyte count) were observed for both HIV-infected and uninfected participants compared to the control group, after controlling for antiretroviral medications, CDC stage of disease and other potentially confounding factors. On the basis of their findings, Goodkin et al. (1998) indicated that this type of bereavement intervention could have positive immunological and health effects following bereavement among HIV-infected individuals.

Goodkin et al. (2001a) conducted an assessment of the same bereavement intervention with another cohort to determine the potential impact of the intervention on plasma viral load. The plasma HIV-1 RNA copy number was measured at baseline and after 10 weeks. There was a significant effect of the intervention on the plasma HIV-1 RNA copy number – independent of antiretroviral therapies, prophylactic therapies against potentially lethal HIV-associated infections, CD 4 cell count, viral load, and CDC clinical disease stage at baseline. Goodkin et al. (2001a) concluded that bereavement support group interventions may be used not only as a primary therapy for psychological distress associated with AIDS bereavement, but also as an adjunctive therapy for controlling plasma viral load in conjunction with highly active antiretroviral therapy.

Memory Boxes

Informants expressed excitement about - and put a lot of faith in - the relatively new concept of memory boxes. Within the last year or so, staff and clients (mainly children) in three of the five organizations had been trained (mostly in group formats) on how to create a memory box. Started originally by a group of women living with HIV/AIDS in Uganda, memory box or book projects have sprung up in community organizations throughout South Africa and have become a popular way to address the needs of children and families affected by HIV/AIDS (Smith, 2004). Because of limited resources and large numbers of children needing psychosocial support, NGOs do not have the capacity to provide individual counseling to all those who need it. A group-based intervention like memory work offers an effective and inexpensive alternative approach to helping children and family members cope with anticipatory grief, death, as well as planning for the future (Smith, 2004).

Morgan (2004) defined memory work as involving "remembering, retelling, recording or sharing". It integrates oral history, narrative therapy and counseling (Denis, 2004). The concept of memory work has many forms and varies across contexts but in a nutshell it involves dying parents and their children working with a social worker, community caregiver, or "memory facilitator" to collect various objects and placing them in metal or wooden box (even a plastic soft drink container). Anything can be put in these boxes including photographs, birth certificates, a letter from the parent, audiocassettes capturing stories and voices, drawings, and mementoes. Children can also decorate the boxes. Another option is to make a memory book and fill it with documents, letters, drawings, poems, family trees etc. Memory boxes and books can be used in support groups and members can share their boxes or books with other members (Blom & Bremridge, 2003). The assumptions underlying memory box work are that it is good for children to know their family history and one way of gaining control over the situation during mourning is through remembering (Denis, 2004). Memory box work is believed to promote resilience in children so that they will not be overwhelmed by the trauma of their parents' illness or death (Morgan, 2004).

The Memory Box Programme was started in 2000 by the Sinomlando Centre for Oral History and Memory Work of the University of KwaZulu-Natal (Denis, 2004). After a pilot study with 12 families in Durban from 2000 until 2002, the programme has grown and since 2002 it has trained NGOs in the methodology of memory boxes across various areas of KwaZulu-Natal. Denis (2004) reported that more than 20 organizations now have partnership agreements with the Sinomlando Centre. The South Coast Hospice began implementing the Memory Box Project at the beginning of 2001 and since then 425 boxes have been issued (Carter, 2004). It has become an important part of the Integrated Community-based Home Care (ICHC) model and it is regarded by the community as an extension of the broad range of services offered by the South Coast Hospice. Carter recommended that in the case of hospices, "a strong and effective home-based care project should ideally be in place before a memory box project is introduced to an area". Furthermore, a Memory Box Project should not be implemented alone but rather combined with various other supportive services such as access to social welfare grants, counseling and caregiving. Carter also stressed that it is advisable for NGOs and other types of community-based organizations to collaborate and network in implementing memory box projects.

In the current study, informants recognized the value of doing these boxes with children and thought that they could be helpful for adults as well. So far, the experiences reported by both staff and clients appeared to be quite positive (even though this activity was often viewed as "very emotional" by both parties). When staff first received training on the memory boxes, "it was for them the very first time to look seriously at these issues. Sometime, they think about them but they don't really examine their feelings and so on." In several of the organizations, the procedure was that once workers had been trained in memory boxes, they were expected to go out and train other workers within the organization as well as people from the community, so there was a ripple effect. An informant commented that memory boxes were also proving to be useful for improving communication between HIV-positive mothers (fathers are usually out of the picture) and their children. Published evaluations of memory box interventions will hopefully appear in the near future.

Individual Counseling

All informants saw the value of offering individual counseling sessions around grief and bereavement issues, but with their huge caseloads this was not always an option. Average caseloads within each organization ran into the hundreds. An informant explained: "I do not have a lot of time to do a one-on-one counseling. The only cases I do are…those very sad cases, those cases that need therapeutic counseling." Strydom and Raath (2005) also commented on the demands placed on counselors who are simply unable to adequately meet the needs of all those affected by HIV/AIDS.

Informants wished that they could do more one-on-one work with clients and one informant gave an example of a session she had recently which proved to be very satisfying. She introduced me to a middle-aged man when I visited her organization. This man was walking around and was coherent but clearly he was in the end stage of AIDS. She told me that recently this man had sat down with her and "talked non-stop" for nearly three hours. She explained:

> He talked about his whole life...He was reviewing his life so that he could say that was my life and happy times, good and bad people, and that my life is now in a box and now I can move on, and if that means that I have to die...I just couldn't believe it.

Another informant spoke about a boy who had been having problems at school and had been expelled several times. Eventually the principal sent him to her. They said this was his last chance. The informant worked with him for weeks and they never spoke about his mother, but then one day the informant said to him, 'Bring me a picture of your mother.' He was being cared for by his granny. The next time he came by he had a crumpled picture in a broken frame and it was wrapped in newspaper. He showed the picture and the informant said, "Tell me about your Mom." This was the first time he had opened up about the loss of his mother. She had been cremated and had not had a proper burial, so the informant organized with his granny and school for him to go back to the farm and do a traditional burial. And apparently, his behavior slowly improved after this.

Funeral Assistance

Sometimes organizations provided assistance with funeral funds to help families bury their loved one. An informant reported:

> They are getting themselves in huge financial debt which almost overrides the grief process...The remaining person is not only paying off a whole lot of debt for funerals but they are worried about how am I going to support eleven children. And so they don't get a chance to grieve.

It was noted that many people they encountered were so desperate that they were forced to bury their loved one in the backyard. In farming areas, they tended to bury the body next to the river. But the graves were usually not deep and there were worries about what would happen when the floods came. Informants also mentioned how people were sometimes buried in "mass graves". Recently, the mortuary in Chatsworth was closed because of a lack of space to handle all the people who have died of AIDS. One informant reported that she had heard of "many, many tragic cases of families coming to identify the body only to find it decomposing (because the mortuary was too full) and we had to do trauma counseling with the family."

Empowering People to Help One Another

In light of the fact that each organization had too few social workers and other professionals to help hundreds and usually thousands of clients, it was not surprising that a lot of the informants' time went into training people (HIV-positive and HIV-negative) from the community in various skills (home-based care and counseling being the most common) so that they could go back into their community and help others. Of course, there were big differences between the five organizations in terms of the size and nature of training programs. In one very large organization, they had just started a pilot project with two "community motivators" who were paid a salary and were involved in mobilizing the community "to take responsibility for the orphans and funding the children in the community in order to have the children remain within the community of origin." A difficulty encountered so far was that when HIV-positive mothers were referred by the antenatal clinics to workers for assistance with future planning for their children, the workers were unable to contact them because the mothers supplied false addresses and phone numbers to clinic staff because of the fear and stigma associated with attending an HIV-related support group.

On a brighter note, another organization that specialized in counseling services had a well-established training program in place and they had successfully trained 500-600 lay counselors over a five year period. As was the case in several other organizations, some lay counselors were now employed by the organization.

A final comment here: all informants noted that few men came to their organization for help and few participated in support groups or income generation projects. One informant said: "I'd love to see more men...but it's not happening as fast as I'd like it to." When asked the reason why men did not join support groups, she suggested that it was because of the "male egos", their belief that it was weak to cry or ask for help, and their tendency to deny problems. An informant described how discouraged she became recently during one of her support groups when a female member (who had AIDS) spoke about being pressured to have a baby by her partner (who also had AIDS) and she didn't know what to do. She said: "He will end up pricking a condom so that she could be pregnant and I am afraid that's what is going to happen with that girl if nothing is done very soon."

Opinions about the Government's handling of the AIDS Crisis

Informants were unanimous in believing that the government had been too slow to respond to the epidemic and were highly critical of both President Mebki's statements as well as those of the health minister. Here are their reactions:

> Oh disgusting!
>
> He did not know one person who died of AIDS?? His own aide died of AIDS. I think that as a President he could have done more for our country in terms of AIDS. He said AIDS is not a problem. He should have been able to say that. He kept on saying that poverty is causing AIDS. He should have said that AIDS is a disease and it's made a million times worse by poverty. But to say that South Africa has not got a problem with AIDS is absolutely ridiculous....We are a democratic society 10 years down the line...and we've still got people who cannot feed themselves.
>
> There is denial at the highest level. And...I don't know why denial is there....There isn't the commitment at the highest level...I mean why else have we got a minister of health who is just so stupid. I'm sorry to be saying this but I never known a medical doctor have the view that she has, and yet we go through reelection and she gets put back into the position....There are millions of people infected with this virus and yet we got somebody who is just a puppet and that's the only thing I can say. I really believe she is a puppet.

> There is such a silence, and because of their silence people on the ground are also silent.
>
> There is total disrespect for the academics, total disrespect! I mean it is just frightening to see what is happening. Look, they funded us and they have been very good to us with funding, so I don't like to complain, but it is like now the rest of the world thinks that ARVs are a reality in this country and they are not. They are not at all. We can't get them.

But informants expressed hope that even though so many people were infected with HIV, "there is a light at the end of the tunnel." They all commented on the importance of not only having greater access to ARVs but also making sure that people had adequate food to take with their pills and that they were capable of being adherent. As one informant remarked:

> ARVs are not the whole answer to the AIDS problem in Africa because with every one good pill taker you got two defaulters and you can't afford to be a defaulter with ARVs. So, if the government is going to roll it out then they must listen to how the NGOs are doing it because the NGOs who are doing it are doing it well...We see people now and just think if we can keep this person alive for two more years it is going to be a reality.

Staff-Related Issues

The HIV/AIDS epidemic in South Africa has not only touched the lives of those infected with the virus and their loved ones, but also the range of providers committed to their care. The professional literature has indicated that providers who assist people affected by HIV/AIDS have to confront numerous stresses associated with the disease including: 1) relentless uncertainty; 2) coping with multiple deaths of infants, children, and young and older adults; 3) bereavement overload; 4) social and even professional disapproval for working with people with HIV/AIDS; 5) neuro-psychiatric complications; and 6) the loss of entire support systems (Dane & Miller, 1992; Garfield, 1995).

Salaries

The issue of low salaries was problematic for all informants and it seemed to me that it was just a matter of time before the informants moved to greener pastures (meaning changing careers or moving overseas). Informants reported that they loved their profession and they obtained enormous personal fulfillment from working with people affected by the epidemic. However, the extremely low salary offered by the NGOs (versus government departments) was demoralizing. One informant commented: "It is very little, and to think that I have to do all this!" In one organization, it was reported that the average length of employment for social workers was six months. An informant remarked that "it is our major problem because clients tend to get annoyed and frustrated because you just started a working relationship and before you know it somebody new is on, and it's really bad." The high turn over and the high case load left insufficient time to "render social work counseling."

Training

Informants expressed interest in developing their skills and indicated that when the opportunity arose they were able to attend workshops on various topics. Several reported attending a workshop on memory boxes but that was the extent of training on issues on grief and bereavement. The average time spent on training on this subject was two hours. One informant remarked that she was invited to do a presentation with Social Work Honours students at a local university. She believed that it had proved helpful to them, particularly in terms of shattering misconceptions about the grief process and also whether it was acceptable for social workers to show their emotions when counseling bereaved clients.

A common sentiment expressed by providers in general (e.g., physicians, nurses, social workers etc) who encounter dying patients is that few have formal training for death-related work (Benoliel, 1987-1988; Dane & Miller, 1992; Sherr, 1995). Some training prior to working with people with AIDS may help providers adjust to the trail of grief that awaits them (Coyle & Soodin, 1992; Scherr, 1995). In the US, social work schools often provide inadequate training in end-of-life care and bereavement counseling (Dane & Miller, 1992; Csikai & Raymer, 2005). We have no published data in South

Africa on the type and extent of training social work students receive about issues relating to dying, death, grief and bereavement, which is an important area when one considers the high mortality rate associated with HIV/AIDS. One of the first studies to look at attitudes and beliefs about death and dying among university students in South African was recently conducted by Makgati and Simbayi (2005). They administered the well-known Lester Attitude Toward Death Scale to a convenience sample of 179 Black second-year psychology students at a university in Cape Town and they were surprised to find that the students held positive attitudes and beliefs about death and dying and they did not fear death as much as their Western counterparts. The authors' attempt to explain this important finding was rather weak and they simply attributed it to "strong cultural influences that still control the lives of these students" (p. 179). They suggested that further research on attitudes and beliefs about death and dying examine the impact of culture. Their assertion that "some of the steps in such counseling [bereavement] are perhaps trivial as these students do not fear death per se" (p. 179) appears to be a leap considering the methodological weaknesses of this study and the lack of adequate discussion of their findings. The authors wisely called for qualitative studies in the future "in order to obtain a more in-depth understanding of attitudes about death and dying than was possible in the present study" (p. 179).

Informants in the current study reported that students doing their fieldwork in their organizations often had a difficult time getting clients to open up and share their feelings. They usually did not know what questions to ask and many felt uncomfortable working with people with HIV/AIDS as well as dealing with issues around grief and death (which would seem to contradict the findings of Makgati and Simbayi, 2005). Consequently, informants reported that many students left the organization after a short period. Diaz and Kelly (1991) insisted that social work students be adequately prepared to deal with death and dying issues including anticipatory grief. Silberman (1991) suggested that social work schools need to permit students to discuss their feelings about death (especially in young people) and how they feel about their own mortality. Furthermore, when faculty members assign students to do fieldwork in HIV/AIDS-related organizations, they should consider students' previous life experiences and attitudes about working with life-threatening illness (Silberman, 1991). In the most recent study of social workers' educational needs with regard to end-of-life care, Csikai and Raymer (2005) surveyed 391 social workers in the US and found that there was "a considerable need for increased content in various aspects of end-of-life care" (p. 67). Just over one-half of participants reported that content in end-of-life care issues was not offered in their social work programmes and only 31% agreed that the content they received was adequate for practice after they had graduated. Participants felt that they needed more training in this area both within social work programmes and continuing education and there was a "need for much more content in cultural and religious/spiritual differences that impact the death experience" (p. 67). Csikai and Raymer indicated that because dealing with death and dying can make social workers feel helpless if they are not educationally prepared, it was not surprising that participants wished for more "concrete interventions and other resources to hold on to when confronting these difficult issues" (pp. 68-69).

Networking

All informants reported that they referred clients to one another. The overall feeling was that each one of their organizations was doing the best it could to help with the epidemic. On occasion when one organization had a surplus of food or something, they would contact another organization and share it with them. Although they acknowledged that there may be a small amount of corruption in some NGOs in general, it was believed that there was more corruption in the government. They shared common complaints such as: "The AIDS money is not coming down", "Organizations like ourselves are battling" and "We don't have funds."

Stress

A significant body of research has developed over the past twenty years examining the impact on providers of working with people infected and affected by HIV/AIDS (Bennett, Miller & Ross, 1995; Lynch & Wilson, 1996; Miller, 2000; Demmer, 2004b). These studies have attempted to identify the stressors associated with HIV/AIDS care as well as document the extent of burnout among providers (Miller, 1995; Cushman, Evans & Namerow, 1995; Oktay, 1992). An insightful and moving account of what it was like to work on the frontlines of the epidemic in the US since the early days was provided by Bayer and Oppenheimer (2000) in their critically acclaimed book *AIDS Doctors*. Unfortunately, we have very little published data to date on the experiences of South African providers who work with people infected and affected by HIV/AIDS (Smit, 2005).

In the current study, all informants commented on how difficult their work was which made their low salaries seem like a joke. They had to confront on a daily basis people in a great deal of distress and this took a toll on them, physically, emotionally, and spiritually. Informants reported commonly feeling helpless in the face of so much need with so few resources to assist them. An informant commented: "How many people can you be able to serve with the little that you have? So you end up having to draw the line and say I can't help you much and it is so painful." Similarly, another informant said: "Seeing them deteriorate in front of my eyes when I know that I can't do anything about it. And they will come today, and they will come another time and another time, again hoping that I might be able to do something."

Garfield (1995) suggested that providers who care for people with AIDS "live and breathe a form of chronic trauma" (p. 261). They may become overwhelmed by the effects of constantly witnessing suffering and multiple deaths and experiencing "the achingly painful feelings of grief and loss" (p. 261). The pain of witnessing repeated deterioration and death cannot be avoided. Because they were exposed to death and dying on such a regular basis, informants in the current study reported that they (and the staff in their organization) had a lot of anxiety around death. As one informant remarked: "It's like living in a ghost world; the world of the living dead." One informant often found herself worrying excessively about the health of her children, and her children picked up on this anxiety. She gave an example of her 10 year old son who had a rash and he came to her one day and asked her if he was going to die of AIDS. An informant reported that staff persons at her organization were experiencing stress on an ongoing basis: "They are being badly affected...and they are taking grief home with them." She said that staff could lose up to three patients a night. They reported not being able to sleep and demonstrated all sorts of displaced anxiety such as thinking they were going to die in a bus on the way to work.

In the 1980s and 1990s, numerous studies identified a major stressor facing AIDS care providers in developed countries as being death and issues surrounding death (Bennett, 1992; Dunkel & Hatfield, 1986; Jue, 1987; Ryan, 1988; Wiener & Siegel, 1990; Bayer & Oppenheimer, 2000). According to Garfield (1995):

> Caregivers on the front lines of the AIDS pandemic may experience moments of horror at the brutality and senselessness of the disease, and at the lack of justice that seems a part of it. You begin to ask questions when you're living with AIDS, even if you're not HIV positive. And death is something you question. Death is something you think about a lot. (p. 163)

In an Australian study, nurses on AIDS units specifically reported stress associated with the lack of a cure, the high number of deaths, identification with patients and relationships with patients, feelings of powerlessness, the nature of the deaths, and ethical dilemmas surrounding death and palliation (Bennett, 1992).

Deciding to work with people with AIDS challenges providers to deal with their own feelings about illness, pain, death, and personal mortality (Glass & Hastings, 1992; Shernoff, 1990). Providers caring for AIDS patients are often uncomfortable with discussing death, and those who continually care for dying persons have just as much difficulty accepting the reality and finality of death as other people, and death is often associated with feelings of loneliness, fear, loss of identity, and sense of rootlessness (Dane & Miller, 1992). An informant reported that in her organization a group session was arranged to help staff talk about the stress of working with patients who were dying. The informant began the session by focusing on the staff persons' own feelings and experiences with death. Within 20 minutes, half the group was crying. The informant reported that she discovered that several of them had lost loved ones to AIDS. She remembered how one staff person became very angry with her and exclaimed that she was supposed to be helping them and not making them cry.

According to Dane and Miller, providers in AIDS settings must understand their own attitudes about death and the afterlife, and their readiness to face their own mortality may hinder or deepen their practice. Garfield suggested that: "our ability to talk with our clients and patients about living with AIDS and dying from it grows in direct proportion to our ability to share our own anxieties with one another" (p. 137).

Implications for Clients

Considering the large number of studies that have investigated stress and burnout among providers in HIV/AIDS care, it is remarkable how little research exists on its impact on client/patient care (Maslach & Ozer, 1995). But a number of authors have cautioned that providers need to be vigilant about their own response and behavior toward HIV/AIDS patients and their loved ones (Dane & Miller, 1992; Garfield, 1995; Emlet, 1992). Providers who decide to work with people affected by HIV/AIDS are likely to confront a variety of stressors, personal and professional issues that may act as barriers to appropriate and humane care (Davidson & Foster, 1995). This is especially true in a setting like South Africa. To protect themselves, providers may develop professional detachment and may need to see these individuals as different from themselves, to avoid thinking about their own vulnerability to death (Dane & Miller, 1992, Davidson & Foster, 1995; Taerk, Gallop, Lancee, Coates & Fanning, 1993). Avoidance or negative attitudes toward clients/patients (for whatever reason) are likely to be matched by a decline in the quality of care (Maslach & Ozer, 1995; Taerk et al., 1993; Shi et al., 1993). Providers who are uncomfortable discussing death may become insensitive to the needs of clients, thus depriving them of the opportunity to deal with their own mortality (Dane & Miller, 1992). If providers are not vigilant, their own grief and unresolved feelings about death can interfere with the goal of providing a safe and accepting environment for the expression of grief. In the current study, an informant fervently believed that it was not an option for her to tune out and not empathize with clients. She remarked: "The day I don't come home and cry about somebody is the day that this is no longer for me."

Coping

Naturally, it is important for providers who work in stressful environments to find ways to cope so that they do not risk burning out. For some informants, it was engaging in relaxing activities like gardening or eating out or maybe doing physical activity and sports. Some found strength in their religious faith. One informant remarked:

> I think it helps having a strong faith. Definitely, I'm further a long my spiritual journey now than I was ten years ago, and twenty years ago I couldn't have coped with the things I cope with now because I lean on God as a crutch, and I also believe in something better.

While most organizations I visited had a vacation policy for staff which averaged 2-3 weeks, one organization had a very generous policy and was able to provide staff with three weeks vacation a year in addition to two months off every three years with full pay. Besides supervision, it did not appear that informants or staff in the organizations received much training or support in the area of stress management. Systematic research is needed to determine the nature, extent, and quality of worksite support given to providers working with people with HIV/AIDS in KwaZulu-Natal.

There has been substantial research in developed countries on ways to support providers caring for HIV/AIDS patients (Emlet, 1992; Ross, 1993; Grossman & Silverstein, 1993). When reading this research one of course needs to be reminded that NGOs in these countries have far more resources to assist employees than would be the case in a setting like South Africa. But what is interesting is that there is a lot of variation in terms of the amount and quality of support offered. Some NGOs offered a menu of worksite support services while others offered minimal or no support. In fact, studies of AIDS care organizations in New York City indicated that approximately 40% actually had no worksite support services (Cushman, Evans & Namerow, 1995; Demmer, 1999a).

The most common strategy to manage burnout among providers in HIV/AIDS care has been support groups (Grossman & Silverstein, 1993; Kalichman, Gueritault-Chalvin & Demi, 2000). These have been implemented across various work settings (hospitals, community-based organizations, AIDS-dedicated units) and with different occupational groups (e.g., social workers, nurses, and physicians). Typically, support groups are facilitated by an experienced mental health professional and usually run for 12-15 weeks (Grossman & Silverstein, 1993). Unfortunately, there have been few studies that have systematically evaluated the effectiveness of support groups for providers caring for HIV/AIDS patients, in terms of coping (Garside, 1993; Hoffman, 1996). However, descriptions of these groups would suggest that they are helpful in encouraging support group participants to share their emotional reactions to their work, identifying and discussing sources of stress in their work, and discussing ways of coping with these stressors (Hoffman, 1996; Grossman & Silverstein, 1993; Murphy, Stewart, Ritchie, Viscount & Johnson, 2000).

There is no doubt that directors of NGOs like those I visited must find viable ways to support employees and provide an environment where they feel comfortable voicing their concerns and anxieties – if they wish to retain these employees. Besides support groups, research indicates that NGOs and other institutions serving people with HIV/AIDS can alleviate stress among employees by addressing paperwork concerns, creating more equitable workloads, improving relationships among staff within the organization, increasing salaries, and addressing supervision issues (Demmer, 1999a; Lert, Chastang & Castano, 2001; Kalichman, Gueritault-Chalvin & Demi, 2000; Gimbel, Lehrman, Strosberg et al., 2002; Demmer, 2002b; Demmer, 2004b).

Rewards

The professional literature has focused largely on the negative aspects of HIV/AIDS caregiving, and there has been scant attention paid to the rewards of this type of work (Barbour, 1994; Elridge & St. Lawrence, 1995). There is no doubt that HIV/AIDS care can be deeply fulfilling (Gimbel et al., 2002). Providers have reported the following sources of satisfaction: providing non-judgmental care to a stigmatized population, providing comfort and support, relationships with patients, providing education, helping family member and friends, and feedback from patients and their families (Nashman & Hoare, 1990; Horsman & Sheeran, 1995; Bayer & Oppenheimer, 2000). Additional sources of satisfaction are organizational commitment, supportive supervision, job involvement and feeling effective (Demmer, 2002b; Gimbel et al., 2002). The perceived rewards of HIV/AIDS caregiving can serve as a buffer against burnout, and administrators have been encouraged to help employees identify rewarding aspects of their jobs and to develop ways to maximize the benefits of this type of work (Bennett, Ross & Sunderland, 1996).

In the current study, the emotional rewards of this type of work were mentioned by all informants. For some, it was the feeling that they were making a difference. One informant reported:

> As much as I am seeing 500 people, but if I can manage to make the difference with only three people or 10 people every time, then I am happy. Sometimes they come back, they are looking better, and others are working and they are looking beautiful. It makes me so happy.

Another informant added:

> They never leave me. I always have their face in my mind and I'm never going to forget them...All I can say is that there is nobody else in this world who will have seen what I've done...and if that's all I do in my life...it gives me a little warmth.

The love and gratitude that clients showed was also a powerful motivator as evidenced by the following statements:

> My biggest reward is my patients. They give you so much love and you don't get that unconditional love from many people.

> They thank me over and over again and they say no one else has ever spoken to me like this. They say 'please can my mother pay you if I die.'

> They are so grateful that someone is there for them at the end of life to share their real feelings that they have never shared before.

> I still remember, it was July and the schools' holidays, and there was absolutely no income coming in. I went into this home and there was no food and I had no food with me and I felt so bad. And all I had were these two blankets and I gave the family these blankets. And I swear it was like giving them a seven course meal. You had never seen such gratitude. It was like these blankets just took the hunger away. They just took the hunger away. You get little snippets of things that have happened to you - where you have had a moment. And that was one of them.

Conclusion

My interviews with a small group of providers in KwaZulu-Natal, Durban provided me with another perspective on what it means to lose loved ones to AIDS. The providers I interviewed were dedicated professionals who had been working for several years on the frontlines with people in KwaZulu-Natal who were infected and affected by the epidemic. They gave input on what it was like for clients to lose loved ones to AIDS as well as what their own experiences were like dealing with this issue. Confronted by the multiple challenges associated with the disease itself, together with political, social, cultural and organizational factors inherent in the context in which they functioned, it is my fervent belief that the informants were doing the best they could. While they did not consider bereavement associated with AIDS to be the most pressing issue in their clients' lives (and understandably so), they were nevertheless concerned about the multi-dimensional impact of such a loss or losses. In fact, they described efforts by their organizations within the last two years or so to address this issue, primarily through memory box projects, and to a lesser extent in general support groups and individual counseling sessions. They were open to developing or expanding services in the future that addressed bereavement, if it was demonstrated that this is what clients wanted and whether their organization had the capacity to do so. One issue that resonated in my meetings with this group of providers was their dissatisfaction with low salaries. Despite the enormous rewards they associated with serving people affected by the epidemic, it was clear that most providers I interviewed were ready to move on to better paying jobs, possibly leaving the social work profession altogether. This is an important factor to bear in mind when considering the future of social work in South Africa, and more particularly when developing ideas for addressing AIDS-related bereavement. In the next chapter, I summarize the main themes that emerged in this study and discuss the implications for future research and practice.

PART FIVE: CONCLUSIONS AND RECOMMENDATIONS

CHAPTER 15

Conclusions and Recommendations

In 2004, South Africa celebrated 10 years of post-Apartheid democracy. This important milestone was overshadowed by the HIV/AIDS epidemic that has devastated this country for the last two decades. South Africa has become synonymous with HIV/AIDS. It has become the HIV capital of the world - having the largest number of people infected with HIV/AIDS. Because of the complex nature of the epidemic in South Africa combined with obtuse government policies and a lack of effective leadership in addressing the epidemic, countless lives have been lost to the virus. Government statistics on mortality associated with AIDS are notoriously unreliable and we have no precise figures on the total number of people who have died of AIDS-related causes but there is no doubt that there are few South Africans (particularly Blacks) who have not been touched in some way by HIV/AIDS.

There is also no disputing the fact that HIV prevention efforts in South Africa have failed - as evidenced by the increasing infection rate, resistance to condom use, and negative attitudes toward those infected by HIV/AIDS. While resources have primarily focused on HIV prevention efforts and only very recently on making ARV treatment more available to those who need it, comparatively little attention has been devoted to addressing the psychological needs of infected individuals and their loved ones, particularly with regard to end of life and bereavement issues. This is the first study, to my knowledge, that has explored the experiences of adults within the South African context with regard to bereavement associated with AIDS. Although the study focused on a small, non-random sample of bereaved individuals and service providers in KwaZulu-Natal, Durban and thus has limited generalizability, it nevertheless offers a new perspective on what it means to be bereaved by AIDS in the South African context. All of the literature on AIDS-related bereavement comes from the West and is based primarily on the experiences of middle-class gay men. Because of the lack of literature on this topic from African researchers and practitioners, I had to rely extensively on empirical studies from the West for background information. But this exercise proved helpful in revealing the differences in AIDS-related bereavement experiences between the two socio-cultural contexts. This variability in experiences with bereavement in the West and South Africa fits the social constructionist perspective by showing that grieving is malleable and "inextricably entangled in culture-based social construction processes" (Rosenblatt, 2001. p. 286).

Before I go further, let me state that because 13 of the 18 participants in the primary sample were HIV-positive, it was often difficult to separate feelings surrounding an AIDS-related loss with feelings and concerns about being HIV-positive. The question is should I have only interviewed participants with the same HIV status? In looking to the professional literature for guidance, I found some studies that only sampled HIV-positive individuals (e.g., Sikkema et al., 2000; Summer et al., 2004;) but the majority used both HIV-positive and HIV-negative participants (e.g., Neugebauer et al., 1992; Martin & Dean, 1993; Folkman et al., 1996). The difference with these studies compared to mine was that they were all quantitative in nature and it was thus easy to test for differences between the two groups. In looking at the very few qualitative studies that have been done on AIDS-related bereavement, I found one study where all the participants were HIV-negative (e.g., Mallinson, 1999) and one that included both HIV-positive and HIV-negative participants (e.g., Wright & Coyle, 1996). Schwartzberg (1996)'s study only contained HIV-positive men but this was not a study of AIDS-related bereavement per se but rather gay men's view of AIDS, some of whom were bereaved. What I found most frequently were qualitative studies where the HIV status of participants was unknown (e.g., Carmack, 1992; Ferrell & Boyle, 1992; Richmond & Ross, 1994).

Most participants ended up having similar demographic characteristics to each other as well as those who bear the brunt of the epidemic in South Africa: women who are Black and poor. I felt that I was able to obtain rich and varied reports from this sample of individuals. It bears repeating that I have no delusions that the findings of this study can or should be applied to the broader population of individuals bereaved by AIDS in South Africa.

My goal in doing this qualitative study was to give voice to a small group of individuals about a subject that is rarely discussed in South African society: what it is like to experience the death of a loved one to AIDS and how to cope with such a loss. Furthermore, I wished to gain an understanding of how AIDS-related bereavement within this group was shaped by the South African context. Rosenblatt (2001, p. 291) stated that "there are enormous differences from society to society (and within societies) in how grief is shaped, the meaning of the shaping, and the consequences of resisting shaping processes." And Klass (1999) insisted that more attention be paid to understanding political and economic factors that influence bereavement. Furthermore, Sikkema et al. (2000, p. 622) suggested that we need "to identify sociocultural factors related to AIDS-related bereavement in order to appropriately tailor coping interventions." I believe that the current study is a step in the right direction.

The Struggle to Survive in the Midst of AIDS-Related Deaths

The ecological perspective suggests the following: individuals are influenced by multiple and interacting factors, individuals are shaped by their environment and they in turn affect their environment, and individuals should not be viewed as pathological or deviant but rather their behavior should be viewed as "understandable responses to a maladaptive social environment" (Pardeck, 1996, p. 5). It was through this lens that I explored participants' experiences with AIDS-related bereavement. Two core themes emerged in the analysis of the interview transcripts and which connected all the categories: silence surrounding HIV/AIDS and the need to subjugate one's grief in response to more urgent life stresses. Figure 15.1 depicts the ways participants responded to an AIDS-related death and factors that influenced their response.

Figure 15.1 Coping with an AIDS-related death in South Africa

Influencing factors

Government policies on HIV/AIDS relating to education, treatment, & welfare.

High unemployment and widespread poverty.

Cultural beliefs about death and grief.

Stigma and denial about HIV/AIDS on all levels (government, community, family, person).

Lack of formal and informal support for those affected by HIV/AIDS.

Gender inequality.

Own HIV status.

Multiple AIDS-related deaths.

Relationship with the deceased.

Past hurts (problems within the family).

Consequences

Little help available from the government.

Need to find a way to survive.

Bereavement overload.

Few opportunities to share grief, especially nature of the death, with friends, family, and others in the community.

Responses

Focus on economic survival.

Suppress grief.

Rely on inner resources (find meaning in the loss, religious faith).

The following factors (on the micro and macro levels) played a key role in shaping participants' responses to an AIDS-related death: the need for secrecy stemming from AIDS-related stigma and denial, economic concerns, gender inequality, availability of support, and concerns about one's own health.

A conspiracy of silence pervaded the lives of participants and participants themselves played an active role in perpetuating this silence. Participants who were HIV-positive were reluctant to disclose their status, even to close family members. The person who was dying refused to disclose his or her illness to participants and when the person died it often came as a shock. At the same time, some participants were in denial that their loved ones had AIDS and were dying or they "pretended" not to know. This resulted in fewer participants being able to participate in caring for their loved one before the death which left some feeling disappointed and regretful. The notion of anticipatory grief which has received so much attention in the Western literature did not appear to be a salient issue among participants, probably because of their denial of AIDS or impending death or collusion in keeping everything secret. Participants reported attending numerous funerals on a yearly basis (almost all due to AIDS) but no-one at any of these funerals mentioned a word about AIDS, primarily because it was frowned upon.

The main reason why participants felt that they were forced to keep their HIV status and the cause of death of their loved one secret was the stigma associated with HIV/AIDS. They knew that stigma existed at the highest level within the government right on down to their own family. So they could not turn to the government for support nor could they turn to their own family, thus creating a deep sense of isolation and loneliness among participants. They perceived the community to be hostile and uncaring to people infected and affected by HIV/AIDS. Some had learnt through previous negative experiences with family members, neighbours and the church that anything connected with HIV/AIDS was shameful, which they internalized to some degree. A few participants had deep-seated abandonment issues from their past and sharing either that they had HIV or had lost someone to the disease would have threatened already fragile relationships with family members, so they kept quiet. Some participants were committed to breaking the silence around HIV/AIDS but their efforts were frequently squashed.

Most participants were unemployed and very poor, and emotional needs tended to take a back seat to the daily struggle to make ends meet. In a sense, grief was a "luxury" - in marked contrast to the situation of middle class, bereaved gay men in the West who have lost partners to AIDS. Several participants experienced increased economic hardship both before their loved one died as well as after.

Gender inequality, which is ingrained in South African society, is reflected in the fact that it is women who bear the brunt of taking care of the sick person as well as dealing with the aftermath of the death and trying to keep the household afloat. Concerns were expressed by participants about the welfare of the children left behind after the loved one died and participants who were HIV-positive also worried about what would happen to their own children when they died.

Participants felt that there was little help of any kind (both financial and emotional) available to those dealing with the consequences of an AIDS-related death. They had minimal expectations of the government and NGOs, and the same was true for family members, neighbours and others in their community. So, basically, they felt they were on their own. Again, this is very different to the bereaved in developed countries like the US who can take advantage of a host of social and psychological support services provided by AIDS service organizations, private practitioners and other types of NGOs. Typically, gay men in those contexts are able to draw support from other gay men within their communities or from their friendship network (if not from their family). As difficult as it is to be bereaved by AIDS in the US for example, we have seen in this study that the environment is much harsher for the bereaved in the South African context.

For those who were HIV-positive, the death of a loved one to AIDS possibly exacted a higher toll on them physically and emotionally than participants who were HIV-negative. Several participants reported that the stress of caring for someone who was dying had a negative impact on their own already fragile health. The death of their loved one together with multiple AIDS-related deaths within their social network heightened their sense of their own mortality which created anxiety. It is possible that some participants distanced themselves emotionally from their loved one due to their own fears about dying.

The key question is how did participants cope? Confronted by poverty and an environment that was unsupportive (if not downright hostile) to those affected by the disease, it appeared that participants engaged in a combination of the following three responses: focusing on daily survival needs, suppressing emotions, and relying on inner resources (constructing meaning from the loss and relying on religious faith).

First and foremost, participants were preoccupied with trying to survive on a daily basis and to feed, clothe and shelter their family, so all their energies were devoted to this challenge. At the same time, another response was to suppress emotions, so that participants could focus on daily survival or alternately because it was too painful or because there was no-one to share their grief with. Because the common feeling was that there was little help of any kind available, participants obtained comfort through two main means: by reframing their loss as something positive (e.g., it had made me stronger and wiser) and by relying on their religious faith to help them understand the loss as well as to draw strength from it as they moved on with life without their loved one and perhaps coped with their own HIV diagnosis. It is interesting to compare these findings to one of the most recent studies on AIDS-related bereavement in the US. In a study of multiple AIDS-related loss among gay men by Oram, Bartholomew and Landolt (2004), participants similarly reported that what was most helpful to them was relying on their own inner resources (accepting the loss, trusting that time heals, and relying on spirituality). However, unlike participants in the current study, they were able to benefit from a good deal of support from others (mainly friends and partners).

The question of whether it is good to suppress one's emotions (also known as repressive coping) in response to stress (especially death) is highly controversial. It seemed to make sense to me why many participants suppressed their grief to varying degrees so that they could focus on their daily survival needs. That did not sound like "avoidance" to me but rather a reasonable response to more urgent life stresses. I personally like Lindstom's (2002) approach which is that we should not pressure the bereaved individual to work through their loss nor should we tell them to completely avoid it. Similarly, Nolen-Hoeksema, McBride and Larson (1997) suggested that it may be unwise to think either too much or too little about a loss and one's response to it. Of course, there is also the important issue of culture. There were some indications from participants and providers that (Zulu) culture dictates that grief and mourning is supposed to end after the funeral. It was difficult to determine to what degree participants suppressed their feelings about their loss because of cultural norms, or to avoid dealing with the pain, or to enable them to focus on more urgent daily stresses. This needs to be explored in future research.

On the whole, my interviews with a small group of providers in NGOs serving people affected by the epidemic in the surrounding areas of Durban proved invaluable in helping me to ask the right questions, confirming hunches or seeking clarification (with the exception of this issue perhaps). An important issue that was confirmed in my meetings with these dedicated and knowledgeable providers was the problem of poverty and how it underscored all issues for those affected by HIV/AIDS. They agreed that the priority for clients affected by the epidemic was economic survival but they were also concerned about clients' emotional well-being living in such a stressful environment.

Leslie Swartz, a prominent psychologist at the University of Cape Town, commented that "it is always important to anticipate that mental health issues may be very low on the agenda of communities and policy-making bodies" (Swartz, 1998; p. 256). He recommended the adoption of a "broad approach" to mental health work; one that expands "the focus of mental health interests to include broader social, economic, and political issues" (p. 260).

Scarce organizational resources (including inadequate staffing) made it extremely difficult for providers to address clients' emotional needs and to provide one-on-one services. One provider noted that even when they offered "grief counseling", there was little interest in it from clients (this person also acknowledged that their NGO had no trained mental health professionals on staff such as a social worker or psychologist). Providers had different opinions about the degree of interest clients showed in sharing their emotions with others and in seeking counseling but what there was agreement on was the importance of developing trust with clients and moving slowly in getting them to open up. All providers expressed interest and enthusiasm in learning more about how to address AIDS-related grief and bereavement issues, and some providers thanked me for making them more aware of and sensitive about this issue. The fact that the majority of the participants in the primary sample felt that it had been a cathartic experience for them ("a relief") and the fact that so many of them reported that this was the first time they were able to talk to someone about their loss, was an indication to me of the importance of recognizing the emotional needs of those bereaved by AIDS and providing opportunities for them to feel comfortable sharing their experiences and receiving support.

Different Contexts, Different Experiences

One can agree that the context of those who are bereaved by AIDS in South Africa is markedly different from the context of similarly bereaved individuals in the West (notably the US where the bulk of our knowledge about AIDS-related bereavement comes from). Since the HIV/AIDS epidemic first began about 25 years ago, the people who have been most affected by it in the West have been gay men whose lives are quite different to the average person affected by the epidemic in the South African context. But firstly, what unites the two groups of bereaved individuals? There is no doubt that those who are bereaved by AIDS in South Africa as well as those in the West (using the US as an example) have experienced ongoing, pervasive loss within their respective communities, and the term "disenfranchised grievers" fits both groups because of the stigma associated with HIV/AIDS and the lack of societal recognition and support in both contexts for those bereaved by AIDS. The pain of losing a loved one to AIDS is made worse by society's treatment of those who are left behind. But here is where the gap widens between the two groups. Those in the US have been able to derive support from within their communities (from friends and partners) as well as from a well-established and vast network of local, state and federal organizations serving gay people and those affected by HIV/AIDS, but the same is not true for South Africans. An individual bereaved by AIDS in the South African context is usually not even able to obtain support from friends or others in his or her social network. Furthermore, and most importantly, the bereaved in South Africa live in an environment that is far more hostile and unsupportive to those affected by the epidemic. The extent of AIDS-related stigma is far greater in South Africa than the US, and the government in South Africa (which admittedly has far less resources to adequately address the epidemic) must take the blame for making the lives of those affected by the epidemic much more difficult through its denialism, silence and indifference. Although there are a number of NGOs throughout South Africa that are dedicated to helping those affected by the epidemic, their ability is severely hampered by lack of funds and the sheer demand for services. So we have a situation in South Africa where not only are the emotional needs of the bereaved less likely to be recognized and addressed either informally or formally, but their socio-economic circumstances are so dire that the daily struggle to survive takes precedence over emotional needs - unlike those in the US where economic concerns do not appear to be an issue that affects the bereavement experience. This leads to the important question: if we acknowledge that in the South African context the bereaved person's life, circumstances, and socio-political environment is vastly different as well as much harsher than those who are bereaved in the West, is it appropriate to apply Western interventions without question to those in South Africa? The obvious answer is no and I will discuss this in the next section.

The Need for an Indigenous Response

In the ongoing debate about the reconceptualization of social work in South Africa and the indigenization of African social work, there has been much criticism (and rightly so) about blindly applying or mimicking Western models, theories and practices to local contexts - which has been the case for many years (Drower, 2002; Osei-Hwedie, 2002; Gray & Allegritti, 2002). The context of social work provision is very different in South Africa versus the West and Osei-Hwedie (2002, p. 313) cites numerous authors who argue that "social work cannot and must not function as it does in the West." In South Africa, the emphasis is on self-help and informal networks and the types of services that are available in the West are very limited here. Osei-Hwedie asserts that social work practice in Africa "deals with human beings in another environment" and African world-views are different from the West because the context (politicial, social, economic, and cultural) is vastly different (p. 314). What there seems to be agreement on among academics in the social work profession in South Africa, is that we need to stop looking to the West for direction (Drower, 2002) and we need to develop "relevant practice" (Noyoo, 2000a). As Gray and Mazibuko (2002, p. 194) asserted, "In South Africa the dominant political view is that the Western model of social work is no longer relevant." This means far less emphasis on individualized interventions that are therapeutic or remedial in nature (e.g. casework) and more emphasis on "developing appropriate developmental intervention strategies, education programmes and solutions at both the macro and micro practice levels" (Gray & Mazibuko, 2002, p. 197). They added that "the socioeconomic context, characterized by huge income disparities...widespread rural poverty and unemployment, provides a clear indication of the need for macro social work intervention and collaborative programmes" (p. 197). According to Gray and Allegritti (2002, p. 324), at this time "there is still a long way to go in developing indigenous social work practice in Africa" and consequently, social workers are challenged to pick from the best of international offerings while at the same time developing and documenting indigenous solutions that may be of value not only to those in the local context but to the rest of the world as well.

How Effective are Bereavement Interventions from the West Anyway?

Accepting that Western-style bereavement interventions should not be mimicked in South Africa or at the very least "imported knowledge must fit the local context" (Osei-Hwedie, 2002), it is nevertheless interesting to examine just how effective these interventions (individual and group) have been in the West to help individuals with grief-related problems. Up to now, four major qualitative and meta-analytic reviews of bereavement intervention studies have been published (Kato & Mann, 1999; Allumbaugh & Hoyt, 1999; Neimeyer, 2000; Schut, Stroebe, van den Bout & Terheggen, 2001), and here are the main conclusions.

First, bereavement interventions have shown very small size effects (meaning that they have had little beneficial impact). Kato and Mann (1999, p. 287) indicated that six of the eight group interventions they reviewed showed "virtually no beneficial effects". They found an overall effect size of .114 across the interventions. This is considered low because the general effect size for psychotherapy for various problems is .8 (Wampold, 2001 as cited in Jordan & Neimeyer, 2003). In their review of 35 bereavement interventions, Allumbaugh and Hoyt (1999) found an effect size of .43 and Neimeyer (2000) reported an overall effect size of .13 across 23 studies. No overall effect size was reported in Shut et al.'s (2001) review of 16 studies because their review was a narrative one.

Second, in some instances, bereavement interventions had the potential to be harmful to some participants in terms of making their grief-related problems worse. Neimeyer (2000) reported about 38% of participants in the treatment condition would have fared better of they had been assigned to the control condition.

Third, most bereaved individuals are likely to improve without the benefit of bereavement interventions. Kato and Mann (1999) reported that all participants improved over time regardless of whether they were in the treatment or control condition.

Fourth, bereavement interventions are likely to have better results with individuals who are at elevated risk for complicated grief (e.g., bereaved mothers, homicide and suicide survivors, people grieving AIDS-related losses). Allumbaugh and Hoyt (1999) reported greater effect sizes in studies consisting of individuals who were at risk for complicated grief. Similarly, Neimeyer (2000, p. 546) indicated that studies that offered therapy for traumatic grief showed more positive effects than studies of "normal grievers". Schut et al. (2001) found modest effects in seven studies that involved individuals at risk for complicated grief but more positive and long lasting results were found in seven other studies of interventions for individuals suffering from complicated grief. They concluded that "the general pattern emerging from this review is that the more complicated the grief process appears to be or to become, the better the chances of interventions leading to positive results" (p.731).

Finally, a dominant theme throughout the four meta-analytic reviews was the general poor quality of studies on bereavement interventions which could have distorted the true benefits of the interventions. Jordan and Neimeyer (2003) identified the following common methodological problems of these studies: absence of adequate theoretical frameworks, small sample size, lack of a control group and random assignment to conditions, and failure to use rigourous measures relating to the grief process. They recommended that future studies of bereavement interventions address these problems and they also recommended that more attention be given to analyzing moderator variables that could influence the effectiveness of interventions, such as gender, time since the loss, prior emotional history and personality of the mourner, and risk status of the mourner (for complicated grief).

Very little empirical research has been conducted on the effectiveness of group interventions that specifically target AIDS-related bereavement. Some studies used a comparison control group (e.g., Goodkin et al., 1999; Sikkema et al., 2004) while others did not (e.g., Sikkema et al., 1995; Pomeroy & Holleran, 2002). There were also differences in terms of sample size. Overall, the results have not been inspiring (taking into account the actual scores reported on various psychological measures as well as limitations due to research design) that a group intervention makes a big difference in the lives of individuals bereaved by AIDS. Furthermore, no follow-up studies have been conducted to assess the long-term effects of a particular intervention. What is interesting is that in a recent Canadian study of gay men who had experienced multiple AIDS-related loss, counseling and support groups ranked the lowest on items that were perceived to be helpful in dealing with these losses (Oram, Bartholomew & Landolt, 2004). The authors suggested that participants may have felt this way because of the scarcity of such services, a lack of knowledge about these services, and prohibitive costs. They also indicated that these men may have become so accustomed to "long-term grief" that they did not think it was something requiring formal intervention.

The Changing Role of Social Work in South Africa

Before proposing ways to address AIDS-related bereavement, I need to provide some background on social welfare policy in South Africa and describe the current role of social work as envisaged by the government. In recent years, there have been a lot of changes in the social welfare arena in South Africa. Government policies in the form of the White Paper for Social Welfare published in 1997 and the release of the Social Welfare Action Plan in 1999 by the Ministry for Welfare and Population Development paved the way for a reorientation of social work practice in South Africa toward a social development approach which places the emphasis on macro-level intervention to reach individuals and communities (Drower, 2002; Noyoo, 2000b; Gray & Mazibuko, 2002; Bak, 2004). South Africa's social welfare system is still in its infancy and it is one of the few countries in the world that is completely changing its welfare system (Bak, 2004; Brown & Neku, 2005). In response to structural poverty, high expectations by millions of poor people, inadequate resources to finance a welfare state and a shortage of social service professionals, the government concluded that the answer lay in social development (Noyoo, 2000a; Bak, 2004). Social development is defined as a process of planned social change that links the promotion of the well-being of the population as a whole to economic development (Midgley, 1995). The White Paper emphasizes "a welfare system which facilitates the development of human capacity and self-reliance within a caring and enabling socioeconomic environment" (Ministry for Welfare and Population Development, 1997, p. 15). The White Paper recognizes that "social development and economic development are two interdependent and mutually reinforcing processes" (p. 10).

Developmental social welfare has been advocated as one way to promote social development and its purpose is to create:

> a humane, peaceful, just and caring society that will uphold welfare rights, facilitate the meeting of basic human needs, release people's creative energies, help them achieve their aspirations, build human capacity and self-reliance, and help them to participate fully in all spheres of social, economic and political life. (Ministry for Welfare and Population Development, 1997, p. 7)

These are admirable aims indeed but things become more complicated when one attempts to understand where social work fits into this new framework. The government has come down hard on the social work profession and it has made it clear that Western style social work is not relevant in post-Apartheid South Africa. Social development and not traditional social work is now seen as the only way to address poverty (Gray & van Rooyen, 2000; Bak, 2004). The value of the profession, as perceived by the government, is diminished within the developmental framework. It has been reported that social work has been dethroned "from its position of pre-eminence in social welfare" and pushed to the sidelines (McKendrick, 2001, p. 107). Social work is now just one of several occupational groups involved in social development, others being social development workers and child care workers. Social work has been left scrambling to justify its existence and to demonstrate that it should be regarded as a key player in the social development process - in the face of government criticism (Bak, 2004). Is it any wonder that the profession lacks confidence and is demoralized, as McKendrick (2001) states? Add to that the ambiguity that exists in the White Paper about the role of social work (Bak, 2004). This has led to intense discussion within the profession in recent years about the role of social work, the use of Western theories and models and the need to develop indigenous materials, the content of social work education, and balancing the needs of the individual with the needs of society as a whole. It should be noted that the "quest for relevance" does not only apply to social work but to other professions in South Africa as well including psychology (de la Rey & Ipser, 2004), sociology (Webster, 2004), and development studies (de Beer, 2003).

While social work scholars in South Africa appear to be united in embracing the social development perspective, the same cannot be said for all practitioners, many of whom have reservations about focusing most of their efforts on community work (Noyoo, 2000b; Mamphiswana & Noyoo, 2000). There are several reasons for this including changing "previous comfortable ways of doing things" (McKendrick, 2001, p. 106), concerns about the "lack of concreteness in the conceptualization of developmental social work or social development" (Kaseke, 2001, p. 107), and inadequacy of preparation for using a developmental approach (Kaseke, 2001; Drower, 2002; Brown & Neku, 2005).

Gray and Mazibuko (2002) reinforced the obligation of the social work profession to embrace the social development approach by finding indigenous solutions to the major social problems affecting society such as poverty, unemployment, illiteracy and HIV/AIDS. To do so, they broadly state that social workers must make "greater use of diverse social work methods, such as advocacy, community development, empowerment, consultation, networking, action research and policy analysis" (p. 199). In their revamped role, social workers must "generate intervention models and development strategies to respond to poverty in South Africa (p. 194). Specifically, social workers must find effective intervention strategies that mobilize community resources (talents and skills, leadership, human energy, and capital and material resources) and emphasize community self-help activities (Abatena, 1995).

While McKendrick (2001) and others have been cheerleaders for social work within the new welfare framework and have tried to instill confidence that the profession can be "a powerful and respected partner in developmental social welfare" (p. 110), we still have a far way to go to make it a reality. There is an urgent need to expand our focus beyond debate, to put words into action and to develop practical guidelines for developing and managing social development projects in South Africa. Descriptions of social development projects are slowly finding their way into the professional literature now, but there is a need for more concrete direction for practitioners so that they can be more effective and committed to this social welfare policy (Green & Nieman, 2003). It should be pointed out that in the West there has been increasing recognition in the social work literature of the relevance of the developmental perspective, but even in this context the perspective remains novel and many social workers (and social work educators) are confused about what it involves in practical, programmatic terms (Midgley & Livermore, 1997).

Practitioners and organizations interested in social development projects that address the needs of individuals bereaved by AIDS may want to consider Green and Nieman's (2003) criteria for successful social development projects: (a) Community members should be involved in all aspects of the design, implementation and management of the project, (b) A group format can serve as a source of support, empowerment as well as learning, (c) Various types of training should be offered to members both before and throughout the project, and (d) New ideas and innovation are essential for the survival of the project. Green and Nieman conclude that individuals and groups become empowered by participating in social development projects by building positive personal relationships and earning an income.

An Ecological Framework for Addressing Bereavement

AIDS is the leading cause of death in South Africa and the intent of this study was to shine the spotlight on individuals who grieve AIDS-related deaths (albeit a small group in KwaZulu-Natal, Durban). Among the many issues that social workers are confronted with in the local context is the issue of how to respond to the needs of those bereaved by AIDS. It is imperative that AIDS-related bereavement be understood in terms of the complex social, political, cultural and economic factors inherent in South African society, and strategies to assist the bereaved must address these factors. The social ecological approach provides a useful framework for addressing the needs of individuals bereaved by AIDS in South Africa. Social ecology is an appropriate framework because of its holistic view of the individual and its emphasis on both macro-level changes as well empowerment, self-help and mutual support. Holistic interventions are needed that are interdisciplinary and emphasize the biopsychosocial approach to HIV/AIDS.

The close relationship between social work and social development is a return to social work practice articulated by Jane Addams who through the Settlement House Movements sought to establish social work as the "conscience" of society by promoting community work, social justice and democracy (Franklin, 1990; Schwartz, 1997). It is also compatible with the ecological approach (which I used as the theoretical framework for my study). This approach emerged in the social work profession in the 1970s and it emphasizes the person-in-the environment perspective, encouraging social workers to "work not only with clients but also with the ecosystems that affect a client's functioning" (Pardeck, 1996, p. 23). The essence of the ecological approach is that social change must occur at both the micro- and macro levels. In making a case for the role of social work in the new welfare paradigm in South Africa, McKendrick states that the ecological approach provides social work with "a model to guide practice that is totally consistent with social development" (p. 108). Furthermore:

> This model provides the rationale and the foundation for redefining the purposes and nature of social work in the context of social development: the focus of social work is not only on changing the individual, or not only on changing the environment, but on both and promoting a better "fit" between people and environments. (pp. 108-109)

The concept of *ubuntu* has become entrenched in the South African government's welfare policies (Noyoo, 2000b). The White Paper for Social Welfare (Ministry for welfare and Population Development, 1997, p. 17) stated the following:

> Each individual's humanity is ideally expressed through his or her relationship with others and theirs in turn through a recognition of the

> individual's humanity. *Ubuntu* means that people are people through other people. It also acknowledges both the rights and the responsibilities of every citizen in promoting individual and societal well-being.

This means that the person exists in the context of the community and the emphasis is on caring for each other's well-being and fostering mutual support (Osei-Hswedie, 2002). This caring "stems from as deep a regard for other human beings as for oneself" (Sewpaul, 1997, p. 6). The ecological approach embraces a similar view with its "person-in-the environment" philosophy and its focus on reciprocal relationships between people, with the environment, and with the various systems within the person's environment.

So far, there have been relatively few concrete examples of South African projects in the literature that address psychosocial issues related to HIV/AIDS and that reflect the social development perspective - one notable example being a project for HIV-positive mothers in Durban, reported by Sewpaul and Rollins (1999). My study should be regarded as a stepping stone to furthering our understanding of this issue. Since we know so little about this issue in South Africa as a whole (not just Durban) and since there is little documentation of efforts that may already be underway by various NGOs and providers to address it, the next step should be to expand the focus of the current study to other areas of the country and with more diverse people (e.g., males, children, people who are HIV-negative, various types of health and social service providers), to engage in further research (both qualitative and quantitative) relating to the areas I have outlined, and to document what currently is being done on a formal and informal basis to address the needs of those bereaved by AIDS. In the next section, I have outlined suggestions in table form that are specific to the NGOs that I visited. This is followed by broad suggestions for addressing AIDS-related bereavement in South Africa. These suggestions are presented mindful of the lack of research on this issue in South Africa as well as the fact that there are bound to be many different types of interventions already in existence in this country but which have not been documented. Thus, these suggestions are not offered as a blueprint but rather they should be considered a flexible guide.

Suggestions for Local NGOs

Here I would like to pinpoint some suggestions that may be helpful to the five NGOs that I visited within the KwaZulu-Natal region in terms of addressing AIDS-related bereavement. Several of the NGOs were clearly applying the developmental welfare framework (in varying degrees) in their mission and practice. It is my belief that based on the interest of community members, clients and providers, a way can be found to either incorporate the issue of AIDS-related bereavement or expand its focus within current activities. Providers were enthusiastic about concentrating more on AIDS-related bereavement and the bereaved individuals that I interviewed certainly appeared to benefit from sharing their experiences and feelings. The main challenge for providers seems to be finding the extra time, money and energy to devote to this task and not knowing where and how to start. The other important issue is the fact that the providers I interviewed seemed to be maxed out, overworked, tired, and dissatisfied with their low pay. Some had indicated that they were looking to move on to greener pastures. Notwithstanding their commitment and dedication, I am not very optimistic that the providers I interviewed will be around in the near future to spearhead efforts that will pull together current and future services in a way that specifically meets the needs of their clients and community around AIDS-related bereavement. My recommendation would be for a group of academics (e.g., social work, psychology, medicine, nursing, economics, anthropology) at the University of KwaZulu-Natal, the University of Zululand and other tertiary educational institutions in the province to hook up with local NGOs and community groups that are interested in more effectively addressing this issue, and to develop mutually agreed upon research and development objectives. Sewpaul and Rollins (1999) described a similar type of project that was developed by staff at the University of Natal and King Edward VIII Hospital in Durban for HIV-positive mothers whose children had been admitted to that hospital. A support group for 13 women was formed and over a period of time, applying the principles of developmental social work, the following objectives were achieved: (a) a peer support network was established where participants could share their experiences, (b) participants were involved in various workshops (as well as how to conduct their own workshops) relating to their being HIV-positive, (c) participants gained a sense of self-efficacy by becoming AIDS educators and giving presentations in the community, (d) participants received training in home-based care, (e) participants were engaged in lobbying activities with another community group and were directly involved in advocacy work by getting the hospital to change its policy on stating AIDS as the cause of death on death certificates because of the stigma and hurt associated with such a diagnosis, (g) networking with a local religious organization to obtain short-term help with counseling and meeting the nutritional needs of their HIV-positive infants, (h) an income-generation project (toy-making) was started but because of several reasons it ceased, (i) a final-year social work student completed her fieldwork training at this project and provided counseling to participants about psychosocial problems (and she gained valuable skills herself on micro-macro levels of social work practice), and (g) participants were involved in participatory research that was supervised by the student and involved evaluating the workshops that they ran. Probably the most difficult challenge was the lack of adequate funding to support the project, especially for developing an income-generation project and for skills-training.

In several of the NGOs that I visited there already were in place closed support groups, skills-training activities, income-generation projects as well as students (social work, psychology, medical) undergoing fieldwork training. These were certainly promising settings for developing strategies that more directly addressed the needs of individuals bereaved by AIDS. Based on the example set by Sewpaul and Rollins, I have outlined in Table 15.1 examples of how the NGOs that I visited could enhance their efforts to address issues associated with bereavement from AIDS. In the next section, I present a more detailed discussion of suggestions for addressing AIDS-related bereavement in South Africa as a whole.

Table 15.1 Suggestions for enhancing bereavement-related services within NGOs that participated in this study

Existing services	Ways to enhance services
Individual counseling and support groups	Develop a better screening method to identify those who could benefit from bereavement counseling and support groups (in light of limited staff or time to engage in these activities). Or identify a local clinician (social worker or psychologist) to refer community members to (for those who are experiencing "complicated grief").
Lay counselors and AIDS educators	Include more information and skill-building on grief and bereavement issues in the training programme for lay counselors and educators within the organization. Encourage them to conduct workshops on this issue themselves (particularly on how the community can be more supportive toward the bereaved). Encourage lay counselors to provide individual counseling and support groups on bereavement issues to community members who need it.
Home-based care workers	Incorporate in their training program information about anticipatory grief, how to emotionally prepare the person and family members for the eventual death, and how to promote communication within families during this period.
Spiritual support	Besides offering spiritual support by a pastor or other religious professional, network with local religious organizations, churches etc to educate both religious personnel as well as congregants about HIV/AIDS and ways they can be more supportive to those affected by the epidemic.
Income-generation projects	Encourage community members to learn additional ways of generating income by networking with local businesses to obtain supplies, internship opportunities, and material assistance.

Student fieldwork training	Students can coordinate a bereavement project or be more involved in various micro-macro activities (e.g., counseling, research, advocacy, creating opportunities for community empowerment and mutual support) that will benefit those bereaved by AIDS. Enable students from various disciplines (e.g., medicine, social work, nursing, psychology) to work together on projects. More collaboration between NGOs and staff at tertiary educational institutions on preparing students better for dealing with death and bereavement issues as well as ensuring that they have the concrete skills to engage in development work.
Research	Create opportunities for community-based participatory research. Collaborate with tertiary educational institutions, community members, staff and volunteers to investigate issues that are mutually agreed upon as relevant to those affected by HIV/AIDS. NGOs and tertiary educational institutions need to find ways to bridge the gap between research and practice.
Lobbying and advocacy	More training and opportunities for staff, community members and students to network with advocacy groups (e.g., Treatment Action Campaign, Basic Income Grant Coalition) and to lobby for structural changes in policies and services that affect those affected by HIV/AIDS (e.g. universal access to ARVs, alleviation of poverty, improving the status of women and the rights of people with HIV/AIDS, combating HIV-related stigma, increasing funding for NGOs).
Membership in professional associations	Staff need to become more active in their respective professional associations (whether it be social work, nursing, etc) to shape social policy and improve services for people affected by the epidemic. Directors of local HIV/AIDS NGOs need to become more united in advocating for structural change and to form alliances with social movements (e.g. TAC).

Suggestions for Addressing AIDS-Related Bereavement in South Africa

In this section, I offer broad, flexible suggestions for social workers who are interested in finding ways to improve the lives of the countless people who have lost loved ones to AIDS in South Africa. These suggestions include individually-oriented interventions like casework, support groups and interventions to explore spiritual needs. But most of the focus, in keeping with the ecological and developmental perspectives, needs to be on advocating for systemic change.

Individual Counseling and Support Groups

There is ample evidence in the literature on AIDS-related bereavement that - at least in the short-term - individuals bereaved by AIDS may have a more difficult time grieving primarily because of the highly stigmatized nature of the disease and the lack of social support available for those bereaved by AIDS. However, there are scant studies assessing the efficacy of individual counseling interventions among individuals bereaved by AIDS. Of course, this does not mean that counseling is not helpful.

Only a handful of studies have been conducted that evaluate the impact of AIDS bereavement support groups, but these have shown only modest improvements in psychological well-being for up to three months after treatment ended. In the past, the focus of social work education in South Africa has been on training students to become caseworkers and "highly skilled therapists", but we have seen that this approach has not been effective in addressing macro-level concerns such as poverty, unemployment and other structural social problems (Mamphiswana & Noyoo, 2000; Noyoo, 2000a; Gray & Mazibuko, 2002). Does this mean that there is no role for casework in South Africa in addressing individual mental health issues associated with AIDS (e.g., complicated grief stemming from an AIDS-related death)? There seems to be agreement (among social work scholars at least) that there is still a role for casework in the developmental welfare paradigm. Mazibuko and Gray (2002) insist that "clinical practice in South Africa remains legitimate" (p. 194), and McKendrick (2001) asserts that "casework will always be a valuable approach that social workers bring to their work" (p. 106). McKendrick adds that casework is "one important ingredient in the developmental social work mix" (p. 109).

Strydom and Raath (2005) indicate that there is a shortage of mental health providers to counsel individuals who are affected by the HIV/AIDS epidemic in South Africa. I agree with this point and we need to lobby the government to find a way to create funding for more mental health personnel (of various kinds).

In the meantime, we are told that South Africa cannot afford a remedial approach where most of the emphasis is on individually-oriented interventions (Mupedziswa, 2001). Considering that counseling and support groups may not be of interest to most individuals bereaved by AIDS (based on the limited evidence that we have) I would suggest that counseling and support groups be made available on a limited basis only to those who need it and who could benefit from it the most. But we must also be cognizant of the fact that individuals who may need or be interested in this type of intervention, may not seek it out because of "lack of courage and means to seek professional help" (Strydom & Raath, 2005, p. 577). So, outreach efforts need to address these issues.

My only concern with the ecological and developmental approaches is that they do not pay enough attention to the immediate needs of individuals in distress who cannot wait 10 or 20 years for social change to happen in order to feel better. The assumption is that we should not focus on individual pathology (Pardeck, 1996). But Bak (2004) indicates that these approaches "may be contradictory to the need to protect the individual, and consider his/her needs for care and support" (p. 86). Perhaps it is for this reason as well as the fact that it is easier to change the individual than society as a whole that local practitioners have had difficulty letting go of the casework approach. Similar sentiments were expressed in a recent study of social workers in KwaZulu-Natal who were questioned for their views on the current status of the social welfare system and the developmental approach (Brown & Neku, 2005). While they saw many positive aspects of the developmental approach, one of their concerns was that they did not feel that it allowed enough micro-level interventions such as casework. I agree with Sturgeon's (1998) view that in social work there needs to be "interventions at all levels of the environment rather than casework or social development in isolation" (p. 311). In countries like South Africa which has a limited social welfare budget, individually-oriented interventions can still be offered as long as great care is taken to match bereavement services with level of need – a cost-effective approach that has been advocated by Walsh-Burke (2000).

Because research has shown that generic bereavement interventions are not effective for the general population of bereaved individuals, Jordan and Neimeyer (2003) suggest that researchers and clinicians concentrate most of their efforts on helping individuals at high risk for complicated grief. Thus, in South Africa, I would suggest that individual or group interventions focus only on those at high risk for complicated grief as opposed to all people who are bereaved by AIDS. At the same time, we need to be mindful that there continues to be a lot of uncertainty regarding the identification of complicated grief as "a distinct diagnostic entity" as well as the lack of valid and reliable tools for assessing those who may be at risk for problematic bereavement (Genevro, Marshall & Miller, 2003). Better screening tools need to be developed for individuals who may be at risk for complicated grief as well as those who may be most likely to need and benefit from bereavement services (Jordan & Neimeyer, 2003). This is particularly pertinent in resource-constrained settings like South Africa.

Let me also clarify that while there is sufficient evidence demonstrating that an AIDS-related death increases the chance that an individual will experience problems coping with grief, we cannot assume that this applies to everyone. Some people will be able to go on with their life just as they would have if they had lost a loved one to another type of illness. According to Sommers and Satel (2005) most people do not need "experts" to guide them through the grief process. But when individually-oriented interventions are needed by the bereaved, it is important to consider what Jordan and Neimeyer (2003) said: "The common and probably most important factor…is the encounter with compassionate and empathically attuned caregivers who provide mourners with a healing experience of being understood and supported in their journey of loss" (p. 780). There is no doubt that individuals grieving a death from AIDS in the South African context need more support and acknowledgement of their loss from others in their community, whether it be family members, neighbours, medical personnel or church leaders. For this to happen, community-wide interventions are required that attempt to change social norms and which teach people how to be kind to one another. In other words, we need more nurturing communities as we find our way through this epidemic.

Training Related to End-of-Life Care, Grief and Bereavement

There are no data, to my knowledge, on the nature and extent of training for South African social work students (or other health professionals for that matter) in the area of end-of-life care, grief and bereavement. This is an important area for social workers to demonstrate competence in, considering the high AIDS-related mortality rate and pervasive multiple loss that exists within South African society (particularly in poor communities) (Strydom & Raath, 2005). It is essential that adequate attention be given to helping students explore their own attitudes toward death and providing them with concrete skills to assist those at the end of life as well as their loved ones so that they feel adequately prepared when they enter the field. There is a critical need for social workers to work with communities in educating them about how to be more sensitive to the needs of the dying as well as the bereaved. But both social workers and other professionals need to be better prepared themselves before they can do this. In a recent report on the status of death education in the US, Wass (2004) concluded that we have a far way to go still in terms of teaching various health professionals to be more competent in this area. She indicates:

> Thus although the contemporary study of death, dying, and bereavement is remarkable in scope and range, the knowledge accumulated has not substantially affected the curricula of the health, counseling, or teaching professions or related disciplines of psychology and sociology. (pp. 297-298)

Considering the lack of research on the psychosocial impact of AIDS-related loss on children, this is another area where social work can become more involved in research, practice, and training.

A final point needs to be made here about broadening awareness about death, dying and bereavement issues beyond the individual. While studies have been conducted that test the effectiveness of workshops or courses on death education, there has been little emphasis on broader interventions that focus on changing community norms and attitudes in this area. A critical shortcoming of the bereavement field is its narrow focus on the individual (probably because psychologists dominate the bereavement literature) without looking at ways to develop more sensitive and nurturing communities so that disenfranchised grievers such as those who have lost loved ones to AIDS do not feel isolated and need to turn to professional help to obtain support which should mostly be coming from family members and others in their social network. While there have been many articles over the years on AIDS-related bereavement, the focus has largely been on individual responses to grief, assessing individual pathology, and suggesting psychological interventions (either counseling or cognitive-behavioural support groups) for treating the individual instead of addressing the root cause (for the most part) of complicated grief for those bereaved by AIDS - a hostile and uncaring environment and stigmatizing attitudes towards those affected by AIDS whether they are gays or members of other minority groups (e.g., drug users, people from the inner-city). Social workers in South Africa have a chance to address this shortcoming by concentrating their research and practice on AIDS-related bereavement at the community level and focusing on societal forces that make the lives of the bereaved so much more difficult (such as stigma, government inaction, pervasive poverty, unequal treatment of women).

Exploring Spirituality

In the bereavement literature, there has been a great deal of interest shown in exploring the link between bereavement and spirituality and a number of publications have addressed this issue ranging from Doka and Morgan's 1993 book *Death and Spirituality* to a special issue devoted to this topic in the journal *Death Studies* in 1999 which was edited by a well-known bereavement scholar in the US, David Balk. In the current study, participants relied heavily on their spiritual faith to both gain meaning from their experience as well as to derive comfort. According to Balk (1999), "bereavement affects spirituality by challenging the griever's very assumptions about the meaning of existence" (p. 486). Although it is not guaranteed that the loss of a loved one will ignite spiritual change, the nature of bereavement holds promise that spiritual change will occur. Balk added:

> Because bereavements allow time for reflection, create a psychological imbalance not readily stabilized, and forever after color one's life, they hold within themselves the potential for spiritual change. In short, they possess this potential because of what they require for a grieving person to become whole again, to be bereft no longer. (p. 490)

What does this mean for social workers helping mainly poor people in South Africa who have lost often many loved ones to AIDS? First of all, it is interesting that little research has been conducted in the US (and elsewhere) on the relationship between spirituality and coping among those bereaved by AIDS. Why this is the case, I am not sure. Looking at the role of spirituality in social work in South Africa, we see that social workers have tended to avoid dealing with this issue in counseling or other interventions (Kruger & Williams, 2003). In their qualitative study of 15 Xhosa women attending a community centre in Cape Town, Kruger and Williams explored the value of spirituality in the lives of poor Black women. Some of the main themes that emerged were: (a) participants derived hope through their spirituality which enhanced their coping capacity, (b) the belief in a higher being empowered them to deal with their problems and strengthened their resilience, (c) meeting others with similar beliefs helped strengthen their support network, (d) participants received practical support (such as food and money for funerals) from the church and church members, and (e) spirituality enhanced their physical and emotional well-being and gave them a more positive outlook on life. Based on these findings, Kruger and Williams indicated that we need to acknowledge the importance of spirituality in social work practice, especially with individuals experiencing extreme poverty and those dealing with "devastating medical diagnoses such as permanent disability, cancer and HIV/AIDS" (p. 356). This means that university departments of social work/development need to pay more attention to preparing students on how to incorporate spirituality into social work interventions.

In light of the fact that so many participants in the current study experienced stigma and lack of support from members of their faith or church leaders with regard to either their own HIV diagnosis or an AIDS-related death, an essential task for social workers is to network and collaborate with faith-based organizations to ensure that people of faith respond more effectively to the needs of those affected by HIV/AIDS. There is no doubt that religion can and has played an important role in social change in South Africa (Erasmus, 2005). A good example of a faith-based initiative that is attempting to address HIV/AIDS issues in South Africa is the Fikelela AIDS Project, an initiative of the Anglican Church in the Diocese of Cape Town. According to Kareithi, Rogers and Mash (2005):

> Fikelela acknowledges that Christian-based responses to HIV/AIDS have not always been appropriate. It is deeply regrettable that there have been instances where Christian FBOs have contributed to the stigma, fear and misinformation that surrounds HIV/AIDS.

Field workers from Fikelela visit churches within the Diocese to mobilize them to form their own HIV/AIDS Task Group and then these groups are involved in various activities ranging from making churches "HIV-friendly", holding candlelight vigils, and providing practical support for the infected and affected. A key component of Fikelela is establishing strategic partnerships with the private sector to raise funds as well as networking with other denominations. It is also engaged in advocacy work and it has a good relationship with the Treatment Action Campaign. Kareithi, Rogers and Mash add that:

> Fikelela builds the capacity of its task groups to engage in dialogue with policy makers, as well as building alliances with other partners in order to amplify the voices coming from the congregational task groups. Partners at these higher levels include the Government departments of Health and Social Services, both of which render aid in the form of funding. (p. 111)

Fikelela was established in 2001 and more faith-based initiatives like this need to develop across South Africa to make individuals more sensitive to those affected by the epidemic as well as to advocate for structural change to improve HIV-related services, reduce poverty, increase access to HIV treatment, and to address HIV-related stigma.

Interventions to Reduce HIV-Related Stigma

While studies focusing on how people with HIV/AIDS in South Africa experience HIV-related stigma are rare (Francis, 2004; Campbell, Foulis, Maimane & Sibiya, 2005), it is certainly not news that stigma is a major obstacle to HIV prevention, treatment as well as support for those infected and affected by HIV/AIDS (Brown, Macintyre & Trujillo, 2003). We have become accustomed to newspaper headlines such as *In S. Africa, Stigma Magnifies Pain of AIDS*, *Experts: AIDS Epidemic Won't Halt Until Stigmas Are Removed, Stigmatisation Now The Biggest Obstacle.* The negative treatment of people with HIV/AIDS and their loved ones constitutes oppression (Francis, 2004). Writing about HIV-related stigma in their study of youth in Ekuthuleni, a periurban area near Durban, Campbell, Foulis, Maimane and Sibiya (2005) assert that stigma serves as an effective form of social psychological policing:

> At the material and political levels, stigmatization of people with AIDS dramatically undermines the likelihood that they or their families will stand up openly and challenge inadequate levels of social recognition and support in a society that often fails to acknowledge even their existence, let alone their needs and rights. (p. 814)

Based on a review of 22 studies that assessed interventions to reduce HIV-related stigma, Brown, Macintyre and Trujillo (2003) concluded that these interventions have shown limited results in changing stigmatizing attitudes – "small scale and in the short term" (p. 49). Although there do not appear to be any studies that have assessed national level interventions to reduce stigma, there seems to be agreement that historically two types of efforts have been most successful in reducing stigma: mobilization by community-based groups of stigmatized members (e.g., ACT-UP in the US and KIWAKKUI - a women's self-help group in Tanzania), and judicial and policy interventions with legal protection and enforcement mechanisms (Brown, Macintyre & Trujillo, 2003; Parker & Aggleton, 2003; Madru, 2003). In South Africa, the Treatment Action Campaign (TAC) shows great promise as a tool to fight stigma. But Campbell, Foulis, Maimane, and Sibiya (2005) indicate that "much work remains to be done to extend the reach of this high-profile organization in South Africa and to mobilize collective action by people in the marginalized communities (such as Ekuthuleni) within which many of the country's people with AIDS reside" (p. 814). Social workers need to become more active in organizations like TAC to address the issue of stigma as well as to lobby for increased government recognition, protection and enforcement of the rights of individuals living with HIV/AIDS, in accordance with South Africa's constitution.

Another strategy suggested by Campbell, Foulis, Maimane, and Sibiya is to facilitate the participation of community groups in critical thinking programmes. These programmes could generate critical thinking about the marginalization of people and the ways in which social institutions and leadership contribute to marginalization. They conclude that community participation in raising critical consciousness that exposes and confronts inequality in society derived from HIV-related stigma should stand alongside education and legislation.

The refusal by government leaders to acknowledge that they have known someone or been personally affected by HIV/AIDS has played an enormous role in perpetuating HIV-related stigma. It will be extremely difficult to reduce stigma as long as the government remains defiant in its denial and silence. At the beginning of 2005, former President Nelson Mandela made a public announcement that his eldest son had died of complications from AIDS. While this highly public (and considerate) gesture was an attempt to fight HIV-related stigma, it did not appear to change people's minds about the disease, unfortunately (Timberg, 2005). At the risk of sounding pessimistic, I believe that we will need a lot more government figures and leaders from other sectors of society to speak up and disclose their personal association with the disease, in addition to more aggressive tactics like specific legislation and collective action by a network of community groups across the country before we see stigma reduced in a meaningful way. As we have seen, stigma plays a major role in making the lives of individuals bereaved by AIDS so much more difficult.

The TAC, which was launched in December 1998, is the most consolidated and organized post-Apartheid social movement in South Africa and it enjoys tremendous popular support. A legitimate role for social workers within a developmental or ecological framework is to engage in social action and to facilitate the mobilization of community groups. As Ungar (2002) asserts, "to take an ecological stance obligates social workers (and their employers) to put into practice their commitment to broad social change through participation in politicized community initiatives and organizations" (p. 493). TAC is an ideal social movement for social workers to align themselves with as a profession – not only to fight stigma but to advocate for others issues relating to HIV/AIDS such as health care and poverty. Social work practitioners need to take on a more activist role; demanding increased access to treatment, fighting stigma and discrimination, and lobbying for increased funding for NGOs and health and welfare personnel, amongst other things. At the same time, social workers can play a more active role in encouraging community members or clients to become involved in these and other social movements (such as the women's movement) because there are various benefits they can get from this. Movements such as the TAC are very effective ways to empower community members (those infected or affected by HIV/AIDS), and empowerment is a fundamental goal of developmental social welfare. Endresen and von Kotze (2005) recently completed a qualitative investigation of the experiences of KwaZulu-Natal/Durban-based TAC activists (many of whom were HIV-positive) and they reported a number of positive benefits that members derived from being part of this group or movement. Activists had developed in-depth knowledge about the disease, nutrition, and treatment options and had learnt about the power of the state and ways to confront it collectively either through protest, partnership building or by taking the fight to the courts. Another important component of belonging to TAC was that it enabled activists to bond with other "equally excluded and socially stigmatized people" and Endresen and von Kotze (2005) added:

> They all talked of how, supported by others, they have taken charge of their own lives and learnt to behave in more life-sustaining ways. Given that the dying and death of friends and comrades in the movement (and outside of it) is a regular feature of daily life, this positive way of being is a crucial change. (p. 436)

Thus, individuals like the ones in the current study could benefit from joining movements such as the TAC to meet a number of needs ranging from emotional and social support to learning how to advocate for better treatment and improved services for those affected by HIV/AIDS. Robins (2004) suggests that:

> Perhaps the most important reason for the successes of TAC's grassroots mobilization has been its capacity to provide poor and unemployed HIV-positive black South Africans with a biomedical and a psychological lifeline, often in contexts where they experience hostility and rejection from their communities, friends, and families. (p. 666)

Combating Poverty

Poverty is the most urgent issue that social workers must tackle, and it is also the most daunting. As I have discussed, poverty overshadows the lives of a large portion of the South African population, particularly those affected by HIV/AIDS. In talking about the impact of AIDS-related deaths on children in Tanzania, Warwick et al. (1998) suggested that macro-economic factors contribute to problems in looking after children bereaved by AIDS and poverty alleviation programmes rather than "AIDS orphan" projects would be a more appropriate method to address the needs of bereaved children. The same argument could be said for individuals bereaved by AIDS in the South African context.

Schenck (2002) urged social workers in South Africa to pay more attention to incorporating Paulo Freire's theories into their practice. We need to more fully engage individuals affected by HIV/AIDS in conscientisation and reflection-action processes so that they can more fully understand how cultural, economic, and socio-political forces impact their lives. As Sewpaul (2005) insists, "if external socio-economic, political and cultural factors are maintaining families in poor, dispossessed and helpless positions how are such families expected to move toward independence and self-reliance within the same structural constraints?" (p. 318). Since the dismantling of Apartheid, there has been little change in the overall level of inequality that exists in South Africa (Nattrass & Seekings, 2001). In fact, some have argued that things have got worse and the poverty gap has widened (Terreblanche 2000 as cited in Sewpaul, 2005).

Income generation projects have become a staple in NGOs serving people affected by HIV/AIDS in South Africa, but more emphasis is needed at the macro-level. The current emphasis of government policy on mutual support and self-reliance is fine as long as it is not an attempt by the state to abrogate its own responsibility in terms of the welfare of its citizens. As Terreblanche and Tshiwula (1996) have pointed out, people cannot lift themselves by their bootstraps if they don't have any bootstraps.

Hope (2004) outlined four broad areas of policy for including Africa's poor in efforts to reduce poverty: (a) job creation and removing restrictions on the informal sector, (b) providing increased access to credit to finance small-scale enterprises and farming activities, (c) governments need to allocate more money in the areas of education and health and improving the access of the poor to health care, education, and social services, and (d) establish "social safety-nets through short-term income transfers to alleviate urgent problems of the poor" (p. 138).

Similar recommendations have been made with reference to the South African context. Motloung and Mears (2002) stressed the need for creating more employment opportunities. Sewpaul (2005) also makes this recommendation but predicts that increasing gainful employment of people is not likely to happen in the near future. Advocating a structural social justice approach to the problem of poverty in South Africa, she proposes a second option which is a universal social security provision in the form of a basic income grant that would be financed through progressive taxation which she believes would be "a non-threatening means of distribution" (p. 19). Whether this will happen is uncertain. Nattrass and Seekings (2001, p. 471) argue that while government economic policies continue to "steer the economy down a growth path that shuts out many of the unskilled and unemployed", voters have remained loyal to the governing party, - the African National Congress (ANC) - and they believe that it is unlikely that "poor citizens will use their vote to effect necessary policy reforms." They maintain that greater redistribution will impose a heavier burden on the working class through higher taxation and possibly lower wages, and will likely meet resistance from "urban labour" and unions. According to Nattrass and Seekings:

> In post-apartheid South Africa, public policy implicitly entails a double class compromise: a capitalist economic system in return for higher wages and some social spending on the urban working and public sector middle classes, and for redistribution through taxation and the prospect of job creation for the rural poor. These compromises are, however, fragile. Both depend on economic growth, and the second requires job-creating growth – to which the government's labour market policies are probably an impediment. (p. 493.

Although we have no way of knowing if or when a basic income grant system like the one suggested by Sewpaul (2005) will materialize, the lesson here is the value of considering alternate ways of thinking that go beyond the individualist-residual and institutional-reformist perspectives (Ife 1999 as cited in Sewpaul, 2005). It is important to consider the social justice perspective when attempting to address issues related to poverty as well as other issues that beset those dealing with the HIV/AIDS epidemic in South Africa such as stigma, and lack of access to adequate support, treatment, and health, and welfare services. According to Sewpaul and Jones (2004), the Global Standards for Social Work Education and Training, which are grounded in a structural, social justice approach, cite some of the following core purposes of social work:

- Facilitate the inclusion of marginalized, socially excluded, dispossessed, vulnerable and at-risk groups of people.
- Address and challenge barriers, inequalities and injustices that exist in society.
- Work with and mobilize individuals, families, groups, organizations and communities to enhance their well-being and their problem-solving capacities.
- Assist people to obtain services and resources in their communities.
- Formulate and implement policies and programmes that enhance people's well-being, promote development and human rights, and promote collective social harmony and social stability, insofar as such stability does not violate human rights.

- Encourage people to engage in advocacy with regard to pertinent local, national, regional and/or international concerns.
- Advocate for, and/or with people, the formulation and targeted implementation of policies that maintain people in marginalized, dispossessed and vulnerable positions, and those that infringe the collective social harmony and stability of various ethnic groups, insofar as such stability does not violate human rights.
- Work towards the protection of people who are not in a position to do so themselves, for example children in need of care and persons experiencing mental illness or mental retardation within the parameters of accepted and ethically sound legislation.
- Engage in social and political action to impact social policy and economic development, and to effect change by critiquing and eliminating inequalities. (pp. 494-495)

Whichever way one looks at it, social workers in South Africa need to be more involved in policy-making and advocating for socio-political and economic changes that will improve the lives of those infected and affected by HIV/AIDS. Shamai and Boehm (2001) called for "special attention to be paid to national politics as an intrinsic aspect of social work intervention in areas where policy may threaten individuals' physical existence or mental existence" (p. 357). Using the ecological perspective, Pardeck (1996) indicated that social workers "have obligations to pursue political changes" (p. 20). Likewise, Gray and Mazibuko (2002) said that social workers using the social developmental perspective must take an active role in policy-making and politics.

Encouraging Men to Play an Active Role in Care and Support

There is a need to shift social norms so that men feel more comfortable as well as motivated to play a more active role in the care and support of those who are ill with HIV/AIDS as well as those left behind. According to Peacock and Levack (2004), while there has been widespread acknowledgement of the burden placed on women in the HIV/AIDS epidemic, there have been few interventions that "explicitly encourage" men to become more involved in care and support activities (p. 184). Men need to be made to feel more responsible (Warwick et al., 1998). There may be several reasons why men have remained relatively uninvolved until now, including pressure to conform to traditional gender roles, not having the knowledge or skills and risking appearing ignorant, and being afraid that their involvement in care and support might lead others to think that they were HIV-positive themselves (Peacock & Levack, 2004). The Men as Partners (MAP) Programme in South Africa has demonstrated that it is indeed possible to get men more involved in social issues. Launched in 1998 in eight of the nine provinces, the MAP programme works to promote gender equality and to reduce the spread of HIV/AIDS. The programme works to effect change through the following strategies: workshops, mobilizing men to take action within their own communities, working with media to promote changes in social norms, collaborating with various NGOs, and advocating for increased commitment from the government to promote positive male involvement. Preliminary evaluations of the Map programme suggest that "given the opportunity and the know-how, many men are eager to challenge customs and practices that endanger women's health and support the well-being of women" (Peacock & Levack, 2004, p. 184). Thus, social workers have an opportunity to develop similar types of community-wide interventions that encourage men to become more aware of and equipped to assist those infected and affected by HIV/AIDS (including caring for the ill and supporting the bereaved).

Bridging the Gap between Research and Practice

Like many other fields, there has been a gap between bereavement researchers and practitioners, with many researchers believing that clinical practice has little to offer the scientific study of bereavement and practitioners thinking that research has little relevance to their work. A recent report from the Center for the Advancement of Health in the US (Bridging Work Group, 2005) has come up with a number of important suggestions for bridging this gap between the two worlds of researcher and practitioner, and this may be of interest to South African researchers and practitioners engaged in bereavement work. I do not wish to repeat all the recommendations in detail, but rather I will summarize them. The overarching theme is that to bridge the gap, both researchers and practitioners have a responsibility to educate and foster communication with each other about their different worldviews, work environments, priorities, strengths and weaknesses. Specific recommendations are outlined for researchers, practitioners, and for educational organizations and training programmes. For researchers, recommendations include:

- Becoming better acquainted with the experiences of caregivers and the delivery of services to dying and bereaved individuals.
- Designing research that is directly related to problems that are considered important to practitioners and consumers of bereavement services.
- Developing teams consisting of researchers, practitioners and consumers who will all be involved in all aspects of the study.
- Paying particular attention to the reliability and validity of measurement instruments.
- Including more discussion of the implications for practice when publishing the research findings.
- Disseminating the findings in various outlets besides journals.

Recommendations for practitioners include the following:

- Make a greater effort to read research studies and attend conferences and workshops.
- Be careful to base interventions on theories and models that have been empirically supported.
- Learn how to become more critical consumers of research.
- Seek out opportunities to collaborate with researchers and consumers in studies.

Finally, for those working in education and training settings, recommendations include: encouraging instructors to focus more of their efforts on helping practitioners become more acquainted with research methodology and how to use research in their work, advising instructors to include research updates in their training courses that may be of interest to practitioners, and providing opportunities for instructors to become involved in direct practice as well.

While the report mentions including the consumer in research efforts, I would like to emphasize this point more and suggest that, in keeping with an ecological or developmental approach, social work researchers and practitioners not only work closer together in HIV/AIDS research and bereavement research but also engage community members and community stakeholders more in these efforts. Community-based participatory research (CBPR) is an alternative model to the top-down technical assistance from experts to practitioners to community members (Smith et al. (2003). A recent example of this model applied to the South African context was provided by Mosavel, Simon, van Stade, and Buchbinder (in press) who established a research agenda relating to cervical health in an under-resourced community in Cape Town. Community members and stakeholders played an active role in identifying concerns and priorities for the community and shaping research questions. We need to reconsider traditional approaches that involve conducting research in a vacuum, disseminating research findings and telling community members how they can incorporate these findings into their lives.

Strengthening the Social Work Profession

These are indeed challenging times for those confronting the HIV/AIDS epidemic in South Africa, including those living with the disease, those who have lost loved ones to it, as well as professionals whose job is to care for those infected and affected by the epidemic. For social workers to be more effective in addressing the concerns of those infected or affected by HIV/AIDS (including the bereaved), some consideration must also be given to finding ways to increase morale among social workers and to strengthen their collective ability as a profession. It is inconceivable to me that social work will be able to make a significant impact on both altering the course of the epidemic and shaping more appropriate responses to it on the micro-macro level, without the profession becoming more consolidated as well as enabling its members to receive a satisfactory remuneration package. It is deeply worrisome to me that there is such a feeling of low morale in the social work profession, particularly against the backdrop of evolving welfare policies. Low morale stems from the changed and uncertain role of social work within the new welfare system as well as low salaries and lack of respect from the government for the contribution of social work to social development. While I agree with McKendrick (2001) that the profession has much to offer social development, the lack of a unified professional association to organize the profession is problematic. Mazibuko and Gray (2004) argue that the social work profession lacks professional unity and they recommend the establishment of a national professional association (like the National Association of Social Workers in the US) as opposed to a handful of separate associations that currently exists. The profession would then be in a stronger position to form alliances with other groups to achieve social change, to formulate positions on developmental social welfare and social work issues on both a national and global level, and to advance the interests of social workers in matters relating to salaries, work conditions and benefits. According to a recent small-scale investigation by Malherbe and Hendriks (2004), social workers in the Western Cape reported that the most important way to increase job satisfaction was an "adequate and fair" remuneration and benefits package.

Future Research

Collaboration between Researchers

Research on AIDS-related bereavement in the South African context is non-existent, and relatively few examples of empirical research on other types of bereavement are available (Strydom & Fourie, 1998). Of course, this does not mean that local social workers have not been involved in efforts to address AIDS-related bereavement in practice. However, their work has failed to be published in the professional literature. It is vital that journals such as *Social Work/Maatskaplike Werk* create opportunities like a "Best practices" or "Notes from the Field" section within their journal that encourage social workers on the frontlines to document and share their experiences and expertise with other practitioners. There are too few articles in professional journals in South Africa (including social work and psychology) written by non-academics. In their discussion on research on HIV prevention in South Africa, Campbell and Williams (1996) suggested:

> Channels need to be developed whereby such knowledge can be more widely circulated both within South Africa and also to and from other

> African countries. Academic journals have a role to play in this process, and academics need to collaborate with health workers and activists in the task of documenting this experience.

In addition to reports of practices and experiences relating to AIDS-related bereavement, there is also a need for empirical research on this subject that is interdisciplinary. Our understanding of issues relating to HIV/AIDS (including bereavement) will be so much richer when viewed from different perspectives and that integrates knowledge from various disciplines (Strydom & Raath, 2005). This is important when one considers that AIDS-related bereavement is not just a psychological issue but rather an experience that is also shaped by social, political, cultural and economic factors.

I recommend that not only should community members and local researchers from different disciplines collaborate on research endeavours pertaining to AIDS-related bereavement, but that there also needs to be some sort of exchange of information and expertise on this subject between local and foreign researchers and practitioners. This has already been done in the arena of HIV prevention in the prison system, where researchers from the South African Medical Research Council and the Department of Correctional Services have forged links with researchers from Emory University in Atlanta, Georgia (Reddy, Taylor, and Sifunda, 2002). Collaboration and research capacity building between researchers from less developed countries and those from developed countries has the potential for advancing knowledge about AIDS-related bereavement in both South Africa and the rest of the world, provided that there is mutual recognition and respect for the talent of all partners. It is also of the utmost importance that collaborative efforts recognize the unique characteristics of the local context as well as the skills and talent that are available in this context. One may question what researchers in developed countries have to offer researchers in a very different context like South Africa; after all, isn't a central theme of this thesis the fact that research findings in countries like the US have limited relevance to the local context? Firstly, I think it would be unwise to totally ignore everything we have learnt about AIDS-related bereavement from the rest of the world – even if the nature of the HIV/AIDS epidemic in those countries differs in many respects from South Africa. At the very least, the body of empirical research gives us a lot of useful questions to ask when we conduct our own research on this topic. Furthermore, the design and implementation of our research can be enhanced based on lessons learned from studies on AIDS-related bereavement elsewhere. One may also ask what can researchers in South Africa offer those in developed countries, in light of the fact that scant research on AIDS-related bereavement has been conducted in South Africa to date. I believe that South African researchers have not had the opportunity to engage in research on this subject because of limited funding opportunities. This does not mean that they lack the expertise or capability to enrich knowledge about AIDS-related bereavement. Rather, with adequate funding, they can generate research based on their extensive knowledge of the complexities of the local context and they have the opportunity to make important contributions to knowledge about the social, cultural, political and economic influences on bereavement - an area where there has been a void in the professional literature on bereavement from the West. The majority of bereavement research from the West has centered on psychological processes and individual pathology and has overlooked another way of examining bereavement – using an ecological perspective. Neither has it explored alternate ways of promoting adaptation to grief among community members beyond individual counseling and support groups. South African researchers (and I include researchers from various disciplines such as social work, anthropology, economics, nursing, political science, psychology, development studies, and adult education) have a unique opportunity to demonstrate the value of interdisciplinary research in promoting a more holistic understanding of bereavement. They can advance our knowledge of bereavement by studying people in a context (i.e., African) that has received little attention in the bereavement literature and finding alternate ways to promote support and healing among the bereaved that is both unique and suited to this particular context.

A suitable venue for researchers and practitioners to learn from one another and possibly create collaborative research partnerships or exchange programmes, is the Association for Death Education and Counseling (ADEC). Based in Illinois, it is an international professional organization dedicated to promoting excellence in death education, care of the dying, and bereavement counseling and support. ADEC is the oldest interdisciplinary organization in the field of dying, death and bereavement. It has almost 2000 members worldwide (though most are from the US) including educators, counselors, nurses, physicians, hospital and hospice personnel, mental health professionals, clergy, funeral directors, social workers, philosophers, psychologists, sociologists, physical and recreational therapists, health well-being specialists and volunteers. ADEC works to promote and share research, theories and practice in dying, death and bereavement (www.adec.org). I have been a member of this organization for 10 years and I would strongly encourage South African social workers to join this organization, as well as other local professionals and NGOs who are interested in this field. ADEC may wish to consider reducing the annual membership fee for individuals and NGOs from less developed countries. I also believe that ADEC needs to do more outreach to other countries around the world to increase international membership.

A final recommendation is that the editors of the two premier peer-review journals in the bereavement field, *Death Studies* and *Omega: Journal of Death and Dying*, should reach out to scholars and practitioners in African countries and develop special issues that relate to bereavement issues in these countries. In particular, it would be wonderful to see an issue devoted to AIDS in Africa and to read about research, theory and clinical issues (e.g., end of life care, death attitudes, grief and bereavement, bereavement care) written from an African perspective.

Research Areas

Here are two broad recommendations, adapted from the report of the Center for the Advancement of Health (Genevro, Marshall & Miller, 2003), for future research on AIDS-related bereavement among individuals in the South African context:

- Determine whether there are unique direct effects of AIDS-related bereavement (versus other types of bereavement) on physical and emotional outcomes amongst individuals.
- Clarify the role played in AIDS-related bereavement by factors such as poverty, politics, HIV status, culture, multiple loss, and resilience and protective factors (e.g., coping styles, the amount and quality of supportive social relationships, philosophical or religious orientations, and the environmental context).

- Explore the short-term and long-term impact of AIDS-related bereavement on children (including both socio-economic and psychological effects).
- Develop and evaluate appropriate interventions to address the needs of children as well as adults bereaved by AIDS.

Future research is also needed to assess the role of social workers in addressing AIDS-related bereavement in South Africa. Broadly speaking, we need to:

- Understand the effects of caring for bereaved persons and experiencing repeated AIDS-related losses/bereavement on the physical and psychological well-being of social workers (e.g., examine the effects of bereavement overload and burnout).
- Investigate current AIDS-related education for social workers, specifically training on death and dying and grief and bereavement.
- Determine what types of practices and interventions are effective in helping individuals bereaved by AIDS in the South African context.

I want to say a little more about the last two recommendations. Saloner (2002) suggests that, because there are fewer than 10 000 registered social workers in South Africa working in a context of several million infected people, the primary role of social workers in the HIV/AIDS epidemic should be disseminating "skills, knowledge and attitudes (SKAs)" to various "professional bodies" broadly defined as "medical professionals, active youth groups, women's projects, the business sector and allied health professionals..." (p. 155). Saloner acknowledges that social workers need to have sufficient training in dealing with HIV/AIDS issues. However, I believe that before we can advocate a role of "AIDS trainer" for social workers, it would seem wise to first conduct an assessment of the nature and extent of AIDS-related social work education in South Africa. The last known survey of this type was conducted in 1992 (van Rooyen & Bernstein, 1992). It would also be prudent to conduct an assessment of the perceived capability of practicing social workers who work with people affected by HIV/AIDS. Such a survey could examine the following areas: (a) perceptions of what would be appropriate preparation for this type of work, (b) self-assessments of their competence to assist clients affected by HIV/AIDS, (c) challenges involved in HIV/AIDS care, (d) training needs, and (e) suggestions for enhancing the role of the social work profession in dealing with the HIV/AIDS epidemic in South Africa.

Epilogue

Death is a normal part of life and so is grief. However, grief stemming from an AIDS-related death may be exacerbated because of a number of factors such as greater social stigma, less social support, a greater reluctance to disclose the cause of death, multiple losses, and the HIV status of the bereaved (Dane & Miller, 1992). Because of the context of AIDS in South Africa, it is likely that bereaved individuals may experience these factors with even greater intensity than those from more developed countries. They have to confront additional stressors that are not commonplace in developed countries, such as a grossly inadequate health and social services, minimal governmental assistance, and extreme hardships in daily living such as lack of food and clean water, inadequate housing, and widespread unemployment (Mitton, 2000).

The future role of social work in addressing the HIV/AIDS epidemic in South Africa is daunting, yet promising. In recent years, social workers and NGOs have taken the initiative and developed innovative community-based programmes (Sewpaul, 2001). But a challenge facing social workers is finding the 'time, energy, and skills' to focus on issues directly relating to AIDS bereavement (Wiener, 1998). And one should not forget about the challenge of finding funds to do so. It is hoped that this study will provide an impetus for more comprehensive attention to the issue of AIDS-related bereavement, both in terms of addressing the needs of the bereaved as well as research. Kasiram and Partab (2002:43) express the opinion that "...death in South Africa is embraced with warmth, care and compassion...". This may be a somewhat simplistic (if not overly optimistic) view, especially when one considers the context of AIDS. Nevertheless, social workers can strive to make this a reality for all those who are suffering the loss of loved ones to AIDS in South Africa.

This has been a deeply personal and moving journey for me and the conclusion of this project is naturally accompanied by a mixture of sadness and relief now that this particular journey is at an end. However, I wonder if this is really the end of the road for me. In fact, I feel a greater responsibility to help those affected by HIV/AIDS in South Africa. Where this will lead me, I am not sure. But what I am certain of is that AIDS is a problem that affects us all and we will be judged not only by what we did to address the epidemic but more importantly what we did not do even though we had the capacity. I believe that the more we give a voice to those affected by HIV/AIDS, the more likely governments will be pressured to respond more effectively.

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