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Quality of Life and Care Providers of People Living with HIV/AIDS

by

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ABSTRACT

This study explores the quality of life of care providers of people with HIV or AIDS. The World Health Organization Quality of Life assessment (WHOQOL) is utilized to examine the quality of life of care providers, and the impact of providing care on particular domains and facets of quality of life. The WHOQOL is administered to twenty-three care providers of people living with HIV or AIDS, and sixty-nine students representing respondents from the general population. This quantitative study is a comparison group, posttest only, exploratory design. Results suggest care providers have poorer assessments of particular aspects of quality of life than students. Significant differences do not exist however, between care providers and the general population in terms of overall quality of life. Implications of this study for researchers and practitioners are suggested.

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Chapter One: Introduction

Statement of Intent

The intent of this thesis is to describe the quality of life experienced by care providers of people living with HIV or AIDS in Alberta.

Background

The Acquired Immunodeficiency Syndrome (AIDS) virus was introduced to the world almost twenty years ago, when an unusual form of pneumonia and an uncommon cancer emerged in young, previously healthy, gay men (Barroso, 1997). AIDS was initially identified in socially stigmatized groups, namely gay men and intravenous drug users (Stulberg & Buckingham, 1988). During the past two decades, the AIDS pandemic has infiltrated many communities, regardless of culture, socioeconomic status, sexual orientation, or gender.

The World Health Organization reports that globally 34.3 million people are currently living with HIV or AIDS (World Health Organization [WHO], 2000). According to Health Canada, by December of 1999, 45, 534 positive HIV tests and 16,913 AIDS cases had been reported in Canada (Health Canada, 2000). According to provincial serological testing in Alberta, the cumulative number of HIV positive people from 1986 – 1997 is 2,976 (Southern Alberta Clinic [SAC], 2000). Of the 996 reported cases of AIDS in Alberta, 681 of those persons have died (SAC, 2000). It should be noted that these statistics cannot accurately reflect the AIDS epidemic, due to changing trends in transmission, underreporting, and insufficient voluntary testing (Health Canada, 2000).

Uniqueness

AIDS is unique for a variety of reasons. The very nature of this virus is fascinating. AIDS is the end-stage disease manifestation of the human immunodeficiency virus (HIV) infection (Schoub, 1994). The HIV virus can be transmitted from person to person through blood, semen and vaginal fluid (Schoub, 1994). The progression of AIDS is uncertain; over the course of the disease a number of episodic degenerations occur. A person can carry the HIV virus with no symptoms for 8-15 years before experiencing HIV symptomatology (a pre-AIDS stage where symptoms are highly suggestive of AIDS) (Schoub, 1994).

Although medical treatment regimens significantly extend the lives of people living with HIV or AIDS (PLWHA) (Sikkema & Kelly, 1996), there is no cure and death is inevitable. Opportunistic infections and tumours mark the irreversible onset of AIDS, which generally last 18 months to two years (Schoub, 1994).

The stigma so venomously attached to HIV/AIDS is another distinguishing feature of this illness:

> AIDS has been constructed according to moral categories in a way that few other illnesses have ever been. It has been widely regarded as a sign of immortality and even a punishment for moral transgression. People with AIDS have been stigmatized, scorned, and shunned as "moral lepers" (Yeo, 1991, p.75).

The stigmatization of people living with HIV or AIDS and their support networks is documented in the literature repeatedly. Indeed, Stulberg and Buckingham (1988) comment "People diagnosed with AIDS, their families, and significant others must contend with a social environment of fear, panic, and moral righteousness as well as with the disease itself" (p.355).

The unique character of this disease is also attributed to the number of social consequences embodied by the AIDS virus. People living with HIV or AIDS and their networks contend with a variety of issues, in addition to the potentially fatal disease. AIDS precipitates "a constellation of issues encompassing racism, poverty, homophobia, sexism, commodified health care (and its availability), censorship, sex, drugs, and death" (Smith, 1991). AIDS differs from other illnesses in the sense that it makes public lifestyles and behaviours (for example, sexuality, both heterosexual and homosexual, and drug addiction) that might otherwise have remained private (O'Donnell & Bernier, 1990).

Care Providers and HIV/AIDS

The interconnectedness of the "infected" and the "affected" cannot be overstated. For each person infected with the AIDS virus, there is also an affected family (Bor, Elford, Hart & Sherr, 1993). AIDS impacts HIV-positive people in a multitude of ways. The AIDS virus also impacts those individuals connected to seropositive individuals. In the immediate future, without a known vaccine and in the absence of a reasonably foreseeable cure, HIV will continue to significantly impact the lives and lifestyles of persons at-risk and those who care about them (Britton, Zarski & Hobfoll, 1993).

Within the caregiving continuum, a number of types of care providers exist: both professional and non-professional caregivers provide assistance to PLWHA. Informal (unpaid, non-professional) care providers play an instrumental role in the provision of care to people with HIV and AIDS (LeBlanc et al., 1997). Within the spectrum of informal care, a provider may be a partner, parent, sibling, friend, relative or volunteer. Informal care providers are fundamental to care recipients as they provide emotional, practical, physical and financial support to PLWHA. However, the wide variety of responsibilities that care providers shoulder are often overlooked. Caregivers provide care to HIV-positive people in a multitude of different ways and occupy a unique role for many reasons.

The advancement of drug therapies and earlier initiation of treatment have led to increased longevity for people infected with the AIDS virus (Wachtel, Piette, Mor, Stein, Fleishman & Carpenter, 1992). The ramifications of medical advancements are important to individuals with HIV/AIDS, and their care providers. With the advent of antivirals which have succeeded in prolonging the health of individuals with HIV, many caregivers will be required to provide greater cumulative assistance and care over the course of the illness (LeBlanc et al., 1997).

Care providers are an essential part of the lives of people living with HIV and AIDS. This caregiving responsibility will increase as more individuals with the AIDS virus maintain HIV status for longer periods of time. Gaps exist in the literature about caregivers for people living with HIV and AIDS, however, despite the knowledge that many care providers will be required in the future. In particular, quality of life (QOL) studies, which examine the impact of caring on several aspects of a person's life, are virtually non-existent in this domain of study. For example, only one example of research utilizing care providers of PLWHA and a quality of life scale is evident in the literature (Rose and Clark-Alexander, 1998).

Quality of life studies can provide a comprehensive view of the positive and negative aspects of a person's life from the individual's perspective. QOL is a complex concept though. The definition, conceptualization and evaluation of quality of life differ by instrument, discipline and purpose of study (Ryan, 1995; Burgess & Catalan, 1991; Grimes & Cole, 1996). Indeed, substantial debate about a variety of quality of life issues appears inherent in quality of life studies.

Many scales exist in the literature measuring either objective or subjective components of QOL, or a combination (Burgess & Catalan, 1991; Grimes and Cole, 1996). Subjective scales can measure various elements, but most commonly include the physical, psychological and social dimensions of quality of life (Burgess & Catalan, 1991; The WHOQOL Group, 1995). The existence of self-assessed, multifactorial QOL instruments provides researchers with the opportunity to evaluate the quality of life of groups such as care providers.

Knowledge of specific aspects of caregiving, such as burden of caring or support of the caregiver is important. Yet, a subjective evaluation of overall quality of life can provide valuable information about caregivers of PLWHA that is not currently offered in the literature. While the majority of caregiving research focuses on specific aspects or attributes of caregiving, QOL studies can provide a comprehensive assessment of quality of life, as evaluated by the care provider him or herself.

This study will examine the quality of life arena to explore how care providers of PLWHA subjectively evaluate their quality of life. The questions this thesis addresses are:

- **What is the quality of life for care providers of people living with HIV/AIDS?**
- **Does the quality of life for care providers differ from the general population?**

The literature suggests several factors that may impact caregivers' quality of life. These include: stigma and social isolation; the intensity of care required by the care recipient; psychological and social consequences; stress and burden; issues related to death and dying; reciprocity between care recipient and caregiver and the importance of sexuality; physical and economic factors related to caring; the significance of support; and the ability to derive meaning from caregiving.

Significance of the Problem

Contributions to Research

There is growing evidence about the potentially negative impact of caregiving on the health and well-being of care providers (Herrman, Schofield, Murphy and Singh, 1994). Yet, there is a lack of literature about the quality of life of caregivers of HIV-positive people. Specifically, this thesis serves to contribute to the knowledge bases of the social work profession and the AIDS community.

Contributing to the social work knowledge base, and the knowledge bases of related disciplines is significant for one specific reason: the AIDS virus represents a complex constellation of issues that social workers and other practitioners currently do not fully understand. Monroe (1994) explains "The increasing ability of doctors and nurses to relieve physical symptoms has exposed the complex emotional, social, spiritual and practical needs of patients and their families as they face the crisis of separation and death" (p.252). The exposure of complex needs obliges the profession to investigate the issues that arise for PLWHA and their care providers.

Existing studies criticize the deficit of AIDS-related knowledge among social workers. In a study to assess social workers' knowledge of HIV infection demonstrated "...the overall pattern of responses indicated that social workers have much to learn about HIV infection" (Peterson, 1991, p.33). Peterson (1991) states "Only if social workers are knowledgeable about the range and impact of this disease will they be able to educate their clients, colleagues, and communities effectively" (p.32). Furthermore, Ryan (1991) interviewed social workers across the United States and reported "Many social workers are still fearful and uncomfortable with people who have AIDS" (p.3). Ryan (1991) declares the social work profession to be "...a critical and as yet untapped resource in the international struggle to meet the challenges of AIDS" (p.4).

Social workers have a professional responsibility to examine AIDS-related issues, in order to understand, support, and advocate for, victims of AIDS and their support networks in appropriate ways. Indeed, "Of all professionals, social workers may be best suited for dealing with the social and psychosocial issues of the AIDS epidemic because of their focus on the fit between the person and the environment" (Stuntzner-Gibson, 1991, p.27). The literature base however, exhibits a deficit of contributions from the social work profession. An examination of the quality of life of caregivers of PLWHA is clearly pertinent to the social work profession.

This thesis also contributes to the knowledge base of the AIDS community. Burgess and Catalan (1991) indicate that "In the field of HIV disease...only a handful of studies have even addressed the issue of quality of life assessment and fewer have presented any detailed empirical research" (p.357). Indeed, little has been done to understand or develop an essential resource: the natural caregiver of those who are infected by HIV (Reidy, Taggart & Asselin, 1991). Although knowledge about the QOL of caregivers is an important contribution to the literature, studies about caregivers and quality of life are almost non-existent.

Populations that Benefit

There are several populations that serve to benefit from an examination of care providers of PLWHA. Research into the quality of life of caregivers is valuable to the care recipients themselves. Turner, Catania and Gagnon (1994) explain "It seems likely that the emotional and psychological needs of AIDS patients would be better met at home among friends and loved ones than in formal, impersonal institutions" (p.1544). Pearlin, Semple and Turner (1988) concur: "many of the needs of AIDS patients are better met in care systems of the community than in the labyrinths of the hospital care system" (p.502). The social support offered by care providers is a potentially powerful resource which can be used to mediate against the stressors of HIV/AIDS and to influence life quality for the person with HIV or AIDS (Friedland, Renwick & McColl, 1996).

Care providers also benefit from such an inquiry into QOL. Tebb (1995) utilized a well being scale for caregivers and reported that "Using the scale validates for caregivers that they need to again think about themselves and their needs and not to internalize frustration" (p.91). Although this study did not use a quality of life scale, one can extrapolate from the study's findings that care providers can find this type of process validating. Tebb (1995) speculates "With the information obtained from the scale, social workers and caregivers can make plans that might again provide the caregivers with some enjoyment in daily life" (p.91). Information from the scale can benefit the daily lives of care providers. In addition, an examination of caregiver quality of life impacts other domains of the caregiver's life. The physical health of caregivers can be indirectly maintained by targeting the emotional well being of caregivers (LeBlanc et al., 1997).

Pearlin et al. (1988) note that "while formal caregivers may also be exposed to stress and its consequences, it is the wellbeing of the informal caregivers that is most at risk, for it is this group that has the greatest emotional stake in the fate of the victim" (p.502). It seems logical then, that if communities seek to maximize and prolong caregiving, they should understand how caregivers manage their substantial role, and evaluate their life quality as care providers. Care provider evaluations of quality of life can be utilized to provide agencies with insight into the perceptions of caregivers, and to aid in the programming and provision of services that may assist these caregivers.

Human service providers have a responsibility to learn more about caregivers' needs and to develop relevant and appropriate services that support them in their demanding role (Carten and Fennoy, 1997). Knowledge about self perceived life quality is a necessary precursor to program creation and implementation. Although there is a body of experience from cancer treatment programs that can be drawn upon, quality of life research that is AIDS specific is needed by those responsible for planning and designing health and social service interventions (Carballo, 1990).

QOL studies encourage health care professionals to focus attention on the positive aspects of people's lives and how they can be strengthened (The WHOQOL Group, 1996). The World Health Organization Quality Of Life Group (1996) notes "In general a consideration of the subjective quality of life is likely to lead to an improvement in the quality of health care" (p.356). It is reasonable to assume these statements pertain to an improvement in the quality of all services, in addition to health care. Researchers concur with the statements made by the WHOQOL Group. With respect to caregivers of children with AIDS, Carten and Fennoy (1997) write "as the number of surviving children in the child welfare system increases – providers must pay close attention to the reported experiences of caregivers and listen to their requests" (p.124). A QOL assessment is one method of "paying close attention".

The benefits informal caregivers provide to formal care institutions also make an inquiry into this population a worthy endeavour. According to Herrman et al. (1994), "the quality of life of informal caregivers is becoming increasingly relevant to clinicians and planners of health, welfare and housing services" (p.131). These authors note that "there is little information on the prevalence or types of the experience of caregiving or about the range of caregivers' responses or service needs" (Herrman et al., 1994, p.132). Limited empirical documentation and theoretical analysis result in an inadequate understanding of social policy and service development in relation to caregivers (Schofield, Bozic, Herrman & Singh, 1996).

With the enormous economic costs of hospital and institutional care, caregivers provide incalculable economic benefits to the community and society by providing care outside of these settings (Pearlin et al., 1988). Turner et al. (1994) argue that the extent and success, or lack there of, of informal caregiving would have considerable consequences for the economic costs of AIDS at the societal level, as the tremendous costs of hospital and institutional care make AIDS a very expensive disease. Quality of life assessments "can provide a key parameter in cost-benefit studies and can thus contribute towards achieving optimal resource use" (The WHOQOL Group, 1996, p.356). An understanding of the QOL of caregivers is economically beneficial to the health care system and other formal institutions.

Purpose of Thesis

The purpose of this thesis is to describe the quality of life assessments of care providers to people living with HIV/AIDS, and how these differ from the quality of life assessments of the general population.

In describing quality of life issues for caregivers of people living with HIV/AIDS, certain questions emerge. Do caregivers of people living with HIV/AIDS differ from caregivers for other conditions/diseases? Are family care providers challenged with specific issues? Do volunteer care providers face specific caregiving dilemmas? What negative aspects of care provision do informal caregivers contend with? Are there positive aspects to providing care?

Factors have been identified in the literature that have relevance in enriching or diminishing the quality of life of informal care providers of people with HIV/AIDS. This list of factors was extrapolated from a review of the literature, and will be used to inform the study. These include:

1. the stigma and social isolation that are attached to the AIDS virus;
2. the intensity of care required by the care recipient with HIV/AIDS, and the "roller coaster" effects of AIDS;
3. the psychological and social consequences of assuming the caregiving role;
4. stress and burden associated with assuming the care provision role;
5. issues related to death and dying;
6. reciprocity between care recipient and caregiver, and the importance of sexuality;
7. physical and economic factors related to caring;
8. the significance of support; and
9. the ability to derive meaning and positive experiences from caregiving.

In the following chapter, each of these factors will be discussed in terms of how they may enrich or diminish the quality of life of care providers.

Organization of the Thesis

The following thesis explores the concepts introduced in this chapter. Chapter Two reviews existing caregiving literature, and discusses potential issues for care providers of PLWHA. The concept of quality of life, and the theoretical framework utilized in this thesis are described in Chapter Three. Chapter Four outlines the study's methodology, research questions, sample and other study parameters. Chapter Five presents the results of this thesis. A discussion of these results follows in Chapter Six, closing with resulting conclusions and implications.

Chapter Two: Care Providers of People Living with HIV/AIDS

Introduction

This chapter provides a conceptual understanding of caregiving. Chapter Two begins with an introduction to the issues for care providers, and a description of caregiver tasks and characteristics. This is followed by an examination of the similarities and differences between volunteerism and family caring. Negative aspects such as the stigma attached to caring, social isolation, and the intensity of care are also discussed. Psychological and social consequences of providing care are described, particularly stressors and burden, and death and dying. The concept of reciprocity and the importance of sexuality are then explained, followed by a discussion about the physical and economic ramifications of caring for someone with HIV or AIDS. The significance of support is described, and the chapter is concluded with a discussion about the positive experiences that can be derived from caring.

Existing Caregiving Literature

The majority of existing caregiving research describes care providers of the elderly, or those with terminal illnesses. Studies primarily address caregivers who are female (Krach & Brooks, 1995), and traditional care providers who are usually older family members in socially and legally recognized relationships with the care recipient (Park & Folkman, 1997). In addition, "the disease of the care recipient is generally not stigmatized and the caregiver does not usually have the same illness" (Park & Folkman, 1997, p.424). Thus, caregiving literature frequently documents traditional caregiving relationships.

There are several points of convergence within the general caregiving literature, however, that are applicable to AIDS caregiving. Clipp and George (1993) state caring for a cognitively impaired older adult constitutes a chronic stress that in many caregivers leads to financial, psychological and physical health consequences. Such stress, however, is not contingent on the length of the caregiving obligation. The duration of care provision is not necessarily associated with negative caregiver outcomes (Clipp and George, 1993).

Other conclusions are significant as well. Rutman (1996) declares that caregivers receive relatively low, or no, wages and are perceived as being low status. In addition to such hardships, care providers are also poorly recognized, and "invisible" (Rutman, 1996). Further, family caregivers rarely control or even foresee the nature and intensity of the caregiving work demanded by the care receiver, and many caregivers must negotiate control with professional caregivers (Rutman, 1996). All of these issues associated with caring apply to HIV/AIDS care providers as well.

A thesis combining HIV/AIDS, caregivers and quality of life is a unique contribution to the current state of the literature. Quality of life studies about people with HIV/AIDS rarely appear (Piette, Wachtel, Mor & Mayer, 1995). Moreover, the majority of studies have examined people with HIV/AIDS from a physical/pharmaceutical perspective (Vanhems, Toma & Pineault 1996; O'Keefe & Wood 1996; Cunningham, Bozzette, Hays, Kanouse & Shapiro 1995).

Although quality of life "...is emerging as an increasingly important phenomenon in health and social science literature" (Wilson, Hutchinson & Holzemer, 1997, p.75), research in the field of quality of life and HIV/AIDS has been slow to develop. Of those research articles examining caregivers of people with AIDS, most explore the experience of formal, or professional caregivers (Silverman, 1993; Barbour, 1994; Gordon, Ulrich, Feeley & Pollack, 1993; Miller, 1995; and McCann, 1997). Quality of life studies for caregivers of people with HIV and AIDS specifically, are virtually non-existent in the literature (Rose and Clark-Alexander, 1998).

The following discussion will illustrate the variety of issues care providers of people living with HIV or AIDS may experience throughout the course of caring.

An Introduction to Issues for Caregivers

Caregivers of HIV-positive people are inextricably connected to the AIDS epidemic. Many researchers recognize the invaluable role care providers play in the lives of HIV-positive people. For example, Rose and Clark-Alexander (1998) explain "No matter the stage of infection, people with HIV/AIDS have many ongoing psychosocial needs. With health care management directed toward community and home care as opposed to hospital care, informal caregiving is an essential part of the care of the chronically ill" (p.58). Although this study is based on caregivers of children with AIDS, Rose and Clark-Alexander (1998) conclude that it is important to protect this resource, by providing caregivers with physical and emotional help.

In another significant study about caregiving partners of men with AIDS, Folkman (1997) notes "most of the opportunistic infections and diseases that mark advanced disease are managed at home with the help of a primary caregiver" (p.1208). The significance of this role cannot be overstated. Folkman writes extensively about AIDS caregiving (Park & Folkman, 1997; Rosengard & Folkman, 1997; Folkman, 1997; Folkman, Chesney, Cooke, Boccellari & Collette, 1994) and her articles document key theoretical and practical elements of caregiving for PLWHA.

A substantial focus of this researcher is the examination of stressors and burden associated with caregiving. Folkman researches the coping mechanisms, the perceived level of burden, and the psychosocial resources of care providers. Results from Folkman's studies show that providing care can be stressful, psychologically taxing and isolating. Unlike many other researchers in the caregiving field however, Folkman also examines the positive psychological states experienced by caregivers. While Folkman primarily conducts research about negative states associated with care provision, she takes a unique interest the positive aspects of providing care to someone with HIV or AIDS.

There is an incredible range of potential issues for care providers of people living with HIV or AIDS. These vary from psychological issues to financial concerns to providing practical assistance to a person with HIV or AIDS. There are many facets to consider in AIDS caregiving research:

- Care Provider Tasks: there are many challenges for care providers, as they attempt to fulfill many practical and emotional roles for the sake of the care recipient.

- Characteristics of the Caregiver: the demographics of this population indicate care providers are a diverse group in terms of age and gender.
- Volunteerism and Family Caregiving: volunteer care providers face many of the same challenges as family caregivers. Differences between groups are found in terms of obligation to the care recipient.
- Stigma and Social Isolation: the fear and prejudice evoked by the AIDS virus has consequences for care providers as well. Caregivers report stigmatization as care providers to PLWHA.
- Unpredictable Symptomatology and Intensity of Care: care providers are faced with several challenges due to the chronic nature of AIDS. Care providers must contend with the inability to anticipate relapses, and the intensity of care required from the caregiver.
- Psychological and Social Consequences: care providers are caring for people with a deadly, stigmatized and demanding disease. The intensity of this care can lead to frustration, anger and guilt, among other feelings.
- Stressors and Burden: the pressures care providers feel through fulfilling their role are immense. These stressors can compound, and increase the burden felt by caregivers.
- Death and Dying: these issues are paramount for AIDS caregivers. Dealing with death and dying is an integral and taxing part of providing care to someone with HIV or AIDS.

- Reciprocity and Sexuality: the close relationship that exists between the recipient and care provider illustrates the interdependency inherent in care provision. The relationship can influence the how care providers and recipients are able to adjust and cope through the difficulties of the illness.
- Psychological and Physical Connections in the Caregiving Experience: a variety of physical factors exist that are inextricably connected to the psychological quality of life of a care provider. Caregiver serostatus and their perceptions of personal vulnerability to AIDS are two examples of this connection.
- Emotional Impact of Caring: providing care can be financially taxing for caregivers, as they often sacrifice income or potential income by providing care.
- The Significance of Support: support for care providers is essential. Positive assessments of quality of life are undoubtedly tied to emotional and tangible support care providers receive from their personal support networks and from health and social services.
- And finally, Deriving Positive Experiences from Caring: finding meaning, strength and fulfillment through caring for someone with AIDS is obtainable. The struggles of caregiving are often mitigated through the creation of positive psychological states.

Each of these caregiving issues will be discussed in sequence in the following sections, in order to illustrate the diversity of facets that are apparent for care providers.

Care Provider Tasks

What do caregivers do? The range of care provision tasks is virtually infinite. Informal care covers a huge range in support -- from purely practical help, to emotional support, or a combination of both (McCann & Wadsworth, 1992). Providing emotional support and comfort to care recipients is often combined with helping recipients with their instrumental activities of daily living (cooking, cleaning, laundry, shopping), helping with dressing, bathing, grooming, getting in and out of bed, and going to the bathroom (Wardlaw, 1994). Care providers also help with heavy lifting, gardening or moving (McCann & Wadsworth, 1992), monitoring and assessing, managing symptoms, and coordinating care (Stujduhar and Davies, 1998). These are varied, yet common tasks.

Caregivers can also be called upon to give advice about health or welfare, for psychological reassurance, for mobility or for accompanying the person to hospital outpatient appointments (McCann & Wadsworth, 1992). Management of financial, legal and personal affairs (communicating with family and medical providers), and provision of in-home medical assistance (administering medications, tube feedings, injections, changing linens/diapers) are additional tasks caregivers frequently fill (Wardlaw, 1994).

In addition to caring for a loved one, caregivers often must maintain full or part time jobs, manage their households, and tend to other family and social demands (Ruppert, 1996). The employment, finances, living arrangements, relationships with friends and family, and the physical and emotional health of the care provider can all be affected by the inherent responsibilities of providing on-going care (Wardlaw, 1994). It is established that care providers undertake a variety of roles and perform many activities for the care recipient. One would therefore expect that such taxing roles and responsibilities would diminish the quality of life of care providers.

Characteristics of the Caregiver

Care providers of HIV-positive persons are a diverse group. Conflicting reports of the primary population of care providers abound in the literature. Pakenham, Dadds and Terry (1995) explain that "given that in Australia the majority of those affected by HIV are gay/bisexual males, there are likely to be more men involved in providing care to infected persons and, hence, more same sex carer-patient dyads than in other chronic illness areas" (p.190). In contrast with other types of illnesses, caregivers of persons with AIDS are more likely to be young adults and are often men (Turner, Pearlin and Mullan, 1998). In addition, unique to AIDS is the overrepresentation of homosexuals, particularly gay men, among caregivers (Turner & Catania, 1997). Provision of care via partners and close friends (generally male) are cited by a variety of authors (Folkman, Chesney, et al., 1994; Friedland et al., 1996; Turner & Catania, 1997).

In opposition, Kadushin (1997) notes, that "while initially gay men with various HIV diagnoses are more likely to seek support from peers than from the family of origin, the role of the family as a source of support becomes more significant as the disease progresses" (p.3). However, a history of conflicting values and attitudes concerning lifestyle and sexual orientation may create barriers that make the family of origin less likely to serve as caregivers (Turner et al., 1994). Instead, many people from the homosexual community have opted for a "family-of-choice", those who take on the roles of the biological family (Britton et al., 1993).

Other authors indicate that all types of caregivers are prevalent in the case of gay male patients: lovers, family members and friends (Clipp, Adinolfi, Forrest and Bennett, 1995; Stajduhar, 1997). Whether family members, partners, friends or volunteers, informal care providers are a heterogeneous group. In a study of volunteer care providers, for example, Cassel and Ouellette (1995) found care providers were gay or heterosexual men or women, HIV positive or negative, and lacking or rich with experience. In the case of AIDS caregiving, a diverse mix of demographic characteristics emerge.

The demographics of the HIV/AIDS caregiver are also unique due to the age of both the care-recipient and the caregiver. Because PLWHA are commonly between the ages of 15 – 49 (Moynihan, Christ & Gallo Silver, 1988), caregivers of people with AIDS often represent particularly young cohorts of the population also. Samples commonly cite average ages of care providers in their mid to late thirties (Wardlaw, 1994; Penner & Finkelstein, 1998). Turner et al. (1998) explain that "while family caregiving usually involves the care of older individuals by those who are younger, in the case of AIDS it usually involves either generational peers or the older generation caring for the younger" (p.139). Caring in the AIDS community is undoubtedly distinct from caring for loved ones with other conditions.

This reality makes caregivers vulnerable to disruptions in important developmental tasks (for example, establishment of career and economic security, and initiation of stable relationships) which can have long-term detrimental consequences (Turner et al., 1994). It is noted that because AIDS caregivers are common among groups in which caregiving is typically "non-normative" and especially disruptive, there are implications for caregivers' ability to effectively give and maintain care, and for their experiences as caregivers (Turner et al., 1994). The complications associated with the demographics of this population make caregivers of PLWHA unique.

Contrary to many other chronic or terminal illnesses, the tasks of PLWHA caregivers, and the profile of the "typical care provider" are significantly diverse. There is no common list of tasks associated with care provision, nor is there an agreed upon population of informal care providers. In fact, as Wardlaw (1994) indicates:

> Although it is possible to define a normative profile of informal AIDS care, such a profile does not do justice to all those caregivers who deviate from it. Moreover, it is virtually impossible to paint a complete picture of the caregiving role for even a single caregiver because of the dramatic ups and downs that are characteristic of the course of HIV infection (p.382).

Despite the diversity in all characteristics of this population, caregiving researchers generally speak of volunteer care providers as distinct from partner or family care providers. The following discussion addresses this dichotomy.

Volunteerism and Family Caregiving

The stigma attached to HIV and AIDS suggests that traditional sources of support, such as family and friends, can reject people living with HIV. For this reason, volunteers play a critical role in meeting the needs of PLWHA (Lindhorst & Mancoske, 1993). One might speculate that distinct differences exist between the care provider who is a volunteer, and the care provider who is a family member, spouse or friend. Many questions arise: Do volunteers experience caring differently? Is the bond between carer and recipient different? Do volunteers "burnout"? Similar to the caregiving literature in general, research about volunteer caregivers to people with HIV or AIDS is scant. Many of these questions are not answered, and the majority of the literature focuses on the motivations, rather than the experiences of caring. The few studies that exist are discussed in the following paragraphs.

What are the similarities between family/spousal/friend care providers and volunteers? There are seemingly more similarities between these providers than differences. For example, volunteers must learn to manage the stigma attached to providing care for someone with HIV or AIDS (Lindhorst & Mancoske, 1993; Snyder, Omoto & Crain, 1999). Like many other caregivers, volunteers must overcome their own negative reactions to HIV illnesses, resulting from homophobia or anxiety about relating to someone with a terminal illness (Lindhorst & Mancoske, 1993). In addition, fear of transmission, anxiety about other problems such as substance abuse or mental illness, and recognizing the responsibility of responding to a person with a fluctuating mental or physical state (Lindhorst & Mancoske, 1993) are common stressors to care providers, regardless of the relationship. Dealing with unexpected lifestyle and cultural differences between the care provider and recipient (Christensen, Reininger, Richter, McKeown & Jones, 1999) are also commonalities.

Volunteers, like other care providers, develop close and personal relationships with the person with HIV or AIDS they are caring for (Christensen et al., 1999). Additionally, they face challenges in providing continued care and support, "...including stress and emotional upheaval as the care partner they have come to know and love experiences increasing health problems" (Christensen et al., 1999, p.434). Volunteers help PLWHA with their household chores, and provide emotional and social support to PLWHA (Omoto & Snyder, 1990; Jimenez & Jimenez, 1990). And, these individuals do so without material compensation (Jimenez & Jimenez, 1990), while expending substantial personal costs such as time, money, and energy by providing care (Snyder et al., 1999). These contributions echo those of the family caregiver. Family/spousal/friend care providers often become serial caregivers or have networks of several friends with HIV or AIDS, and this exists with volunteers as well (Penner & Finkelstein, 1998).

What are the differences between family/spousal/friend care providers and volunteers? A noticeable difference is that volunteers more easily drop out or disengage themselves from the caregiving role (Claxton, Catalan & Burgess, 1998; Nesbitt, Ross, Sunderland & Shelp, 1996). Unlike many family, spousal or friend caregivers, volunteers can relinquish their role. This is not to imply that family caregivers do not cease to provide care in some circumstances, but that the agency bond, rather than the obligatory bond to a loved one, may be easier to break. While this may be true, it also stands to reason that due to the bond built between the provider and recipient in the volunteer instance, many volunteers may continue their role, despite the stress of caring.

A second point by Claxton et al. (1998) is that volunteers usually have less contact with the recipient. Indeed, that would seemingly diminish the stress involved in caring. This point too, however is open to debate, as many volunteer care providers spend countless hours assisting the care recipient. The care provision continuum displays a diverse cross-section of care, which varies from care provider to care provider, on the basis of relationship, symptomatology of the recipient, other responsibilities, requests of the care recipient, among many others. The preceding paragraphs illustrate the complex issues faced by care providers, regardless of the provider's relationship to the recipient.

Stigma and Social Isolation

Many medical conditions invoke notions of sickness, pain or death. The AIDS virus in particular represents a constellation of fear, stigma and prejudice. The stigma and isolation that is attached to this disease is often assigned to the care provider as well. The AIDS virus brings to the fore, "a whole range of issues which are linked with social taboos in Western society, including sex, particularly homosexual sex, drug abuse, racial discrimination and death" (Beedham and Wilson-Barnett, 1993, p.75). HIV is attached to values about sexuality, religion and lifestyle (Britton et al., 1993), and results in prejudice, ostracism, harassment and oppression (Beedham & Wilson-Barnett, 1993). HIV/AIDS is the most value-laden disease communities contend with today.

Powerful emotional reactions from family and friends, such as grief, shock, sadness, anxiety, helplessness and anger, are frequently observed (Lippmann, James and Frierson, 1993). The family of persons with AIDS often experiences both guilt and grieving (Stulberg & Buckingham, 1988). Care providers regularly accompany the care-recipient through the process of disclosing the recipients' status, and addressing reactions from family and friends. The stigmatization and isolation that often result are major stressors for the care provider and recipient (Lippmann et al., 1993).

Indeed, care providers report avoidance and rejection by those previously regarded as good friends to be both disturbing and common (Reynolds & Alonzo, 1998). In a qualitative study of family caregivers of PLWHA, Stujduhar and Davies (1998) found all participants in their study experienced stigmatization in one form or another – they dealt with prejudice, loss of friendships and relationships, and living with secrecy from friends, relatives, and health care providers. Sources of stigmatization can be found throughout the care provider's support network.

Despite public education, the fear and loathing surrounding this disease remains pervasive and threatening (Hicks & Rundell, 1996). Rosengard and Folkman (1997) summarize the stigmatized nature of caregiving for an HIV-positive individual:

> The social stigma that is often associated with homosexuality and AIDS may lead to feelings of isolation and inadequate social support during caregiving, which is a time of tremendous stress and burden. This isolation and paucity of support may, in turn, lead to depression and hopelessness and this can be exacerbated if the caregiver is also HIV-positive and dealing with his own disease. Ultimately, the ill partner is likely to die and the caregiver becomes bereaved (p.374).

Caregivers may choose to conceal the serostatus of the care recipient in an effort to protect the individual from the stigma attached to this disease. Living in secrecy serves to protect oneself and the person with HIV or AIDS from negative judgements, rejection, ridicule, and discriminatory acts (Brown and Powell-Cope, 1991). Due to these devastating consequences, care providers have a vested interest in anticipating others' responses and in planning accordingly. Anxiety about disclosure can become obsessive and induces stress and hopelessness (Lippmann et al., 1993). Thus, dealing with the sadness invoked by this disease is compromised by fear, mistrust, stigma, shame, anger and hopelessness (Lippmann et al., 1993). Caregivers acting as the "protective agent" to the care recipient expend additional energy to protect the recipient and self. The unpredictable and intense demands of this disease can also deplete the resources of the care provider, as is demonstrated in the following section.

Unpredictable Symptomatology and Intensity of Care

"Living with AIDS is no longer an exercise in wishful thinking", declares Getzel (1991, p.7), as active interventions such as more efficacious antiviral treatments, immune-modulating medications, and prophylactic treatments of opportunistic infections become available. People living with HIV and AIDS anticipate longer life spans than previous victims of the disease. In fact, Walker, Pomeroy, McNeil and Franklin (1996) characterize AIDS as a chronic illness, as the interim from diagnosis to death has been greatly extended for victims of AIDS. Several challenges for people with AIDS and their caregiver are rooted in the chronic nature of the disease: numerous remissions and relapses, elaborate treatment regimes and their side effects, and recurring dilemmas surrounding decision making and treatment choices (Walker et al., 1996). The caregiver participates in a complex and unpredictable journey with the care-recipient.

AIDS remains a complex disease that has a wide range of stages from asymptomatic periods to those requiring frequent, intense health interventions (Rose and Clark-Alexander, 1998). Canadian researchers, Reidy et al. (1991) state "AIDS is, on one hand, a terminal disease with severe signs and symptoms which requires frequent and intensive medical intervention; and on the other hand, it is a progressive chronic disease which necessitates long-term family commitment and involvement" (p.332). The physical plight of people living with HIV/AIDS is virtually inconceivable. Fatigue, sleep disturbance, pain, profound weight loss, malnutrition, depletion of body mass, night sweats, oral thrush, rash, anxiety and depression (Chesney & Folkman, 1994; Sikkema & Kelly, 1996) are common effects of the AIDS virus. In advanced stages of HIV disease, the range of sequelae includes chronic and severe diarrhea, wasting, dyspnea, severe musculoskeletal pain, neuropathies, blindness, and dementia (Folkman, Chesney, et al., 1994).

Different types of physical and mental consequences of the AIDS virus influence the amount of care required. For example, Milanese, Abeni, Cancelli, Brancato, Fabrizi, Borgia, Perucci and Rocchi (1997) found people with AIDS-dementia complex, toxoplasmosis, wasting syndrome and cytomegalovirus retinitis required more home care visits than those with Kaposi's sarcoma or other diseases. These authors conclude: "Care for PWAs differs, therefore, according to various parameters. The most important of which seems to be the HIV-related disease identified at the outset of the home care programme" (Milanese et al., 1997, p.32).

The "roller-coaster-like" course of the disease implies that people with HIV eventually must endure unrelenting, continuous assaults of the disease, which generally require long and frequent hospitalizations, and lead to physical and emotional exhaustion both for the person with AIDS and the care provider (Stulberg and Buckingham, 1988). As HIV disease progresses, it affects every dimension of quality of life, "including role functioning, social functioning, physical functioning, mental health, general health perceptions and bodily pain" (Chesney and Folkman, 1994, p.167). The care provider is responsible for navigating and supporting the person with HIV/AIDS through this difficult journey.

Psychological and Social Consequences

Care providers are on call, often 24 hours a day (Folkman, 1997). They often endure relentless schedules and tasks associated with caring for a loved one with HIV/AIDS. Ruppert (1996) explains that caregivers are often expected to transform themselves into healthcare paraprofessionals virtually overnight, taking on roles of nurse, physician, therapist, teacher, advisor, social coordinator, and friend. Pearlin et al. (1988) concur: "Depending on the stage of the illness process, of course, the caregiver may be called upon to act as friend and confidant, lover, housekeeper, nurse, and paramedic…In short, the notion of role overload finds quintessential expression in AIDS caregiving" (p.306).

In a qualitative study about the caregiving process, Brown and Stetz (1999) found the labour of caregiving begins at diagnosis or when a care recipient first becomes symptomatic, ill, or debilitated from treatment, and continues until after the person dies. Care providers proceed through four phases of caring: becoming a caregiver, taking care, midwifing the death, and taking the next step. Caregivers in this study indicated their involvement deepened as they faced changing demands of the illness trajectory: "The course of deterioration was experienced as a descending staircase with sets of 'landings'" (Brown & Stetz, 1999, p.187).

The AIDS virus invokes a wide range of reactions, and manifests itself in a variety of ways. HIV provokes feelings of guilt, uncertainty, anxiety, panic, mood fluctuations, grief and loss of the future, fear and the cloak of secrecy (Melvin & Sherr, 1993). Feeling overwhelmed, frustrated, fatigued, exhausted or angry is understandable and common for individuals assuming the caregiving role (Ruppert, 1996). When one considers the multitude of demands on the care provider, it is hardly surprising. These demands can lead caregivers to neglect their own physical, mental, emotional and spiritual needs, which can create a vicious circle, whereby demands persist and the caregiver's energy is drained (Ruppert, 1996).

According to a study by LeBlanc et al. (1995), AIDS caregivers are in great need of emotional support. Using a sample of almost 500 care providers, these researchers found caregivers face chronic stress in the role of caregiver, and experience depressive symptomatology. The caregivers in this sample also exhibited high rates of psychotherapy use, far higher than estimates for the general population. Other researchers found similar results. In a study involving low-income female PLWHA caregivers, Flaskerud and Tabora (1997) found care providers in their sample had significant mental and physical health problems, and experienced loneliness, loss, anger, isolation, and stigma.

HIV/AIDS caregiving is described as an intense, emotional and powerful experience, filled with pride and enrichment on one hand, and anger and disillusionment on the other (Stajduhar and Davies, 1998). "Increasing demands of personal care, threats of contamination, anticipatory bereavement, and the stress of living either secretly or openly with a stigmatized disease" are common sources of discontinuity for care providers (Clipp et al., 1995, p.10).

Pearlin et al. (1988) write that the caregiving role "is increasingly demanding as AIDS progresses, it pushes against the limits of energy, it is relentless, it is emotionally depleting, and, eventually, it is defeating" (p.506). Many caregivers of people with AIDS have never taken care of a seriously ill person before, nor have they seen someone die (Folkman, 1997). With no cure for the AIDS virus, an unfortunate consequence of providing care is eventually saying goodbye.

Stajduhar (1997) describes the "personal work" of caregivers, including reconciling that a loved one will die, making life-and-death decisions, and letting go. Care providers may encounter fear that they will face an early death from the same disease, the stigmatized nature of AIDS, the potentially restricted range of family and spiritual supports and the fact that same-sex relationships are not formally recognized or sanctioned in many social contexts (Kelly, 1998). Tension between professionals and informal caregivers has also been documented as a detrimental reality in HIV/AIDS care (Johnson, 1995). There are particular social and psychological issues related to caregiving for PLWHA that are worthy of further exploration. Among the key factors are stressors and burden, which are discussed in the following section.

Stressors and Burden

The stress experienced by AIDS caregivers is distinct in terms of many social, psychological and physical consequences. Knowledge about other caregiving populations does not fully apply to HIV/AIDS caregivers (Pearlin et al., 1988). In a study examining factors associated with caregiver burden, Folkman, Chesney, et al.

(1994) note five distinct ways that caregivers of people with AIDS often differ from traditional caregivers:

1. caregiving partners of gay men with AIDS are usually male;
2. many caregivers tend to be young or middle-aged;
3. many primary caregivers of men with AIDS are themselves at risk for AIDS or becoming HIV positive;
4. the relationships of gay partners are informal and often stigmatized; and
5. AIDS is stigmatized and caregiving activities are often hidden from members of the general community and even family members.

Hughes and Caliandro (1996) report in a study about caregivers of children with AIDS, "When the caregivers in this study were compared with normative groups, caregivers reported higher than average hassles, domestic and vocational stressors, and levels of depression, anxiety and hostility" (p.354). HIV/AIDS care providers noticeably differ in terms of stressors from other caregiving populations.

Pearlin et al. (1988) identify three types of stressors for friends and lovers who are caregivers that create a "snowball" effect. Although this article is relatively dated and written anecdotally, its findings and conclusions have been verified in other research. One type of stressor for caregivers involves pressures within the caregiver role itself (such as the demands and burdens encountered in housekeeping and nursing activities). The second involves the uncertainties caregivers experience concerning their own future (for example, exposure to the same set of health risks), and the third involves the creation of stressful problems in other roles (such as employment). These authors explain that the demands of AIDS caregiving can disrupt multiple areas of life, including occupational, economic and social.

Once the stressors associated with AIDS caregiving emerge, they can become independent sources of stress (Pearlin et al., 1988). As problems in other realms of the caregivers' life emerge, they can add to anxiety and depression for the caregiver (Pearlin, et al., 1988). Thus, a caregiver can carry the burden of providing care for a sick individual, and the added weight of job problems, economic problems, the abandonment of interests and the attenuation of important relationships (Pearlin et al., 1988).

Pearlin et al. (1988) refer to these stressors as attendant life strains, because for the caregiver, problems in one pivotal role are likely to cause problems in other roles. Furthermore, a multiplication of detriment may ensue. These authors remark "...as problems in these roles mount, each becomes an independent source of stress and incrementally adds to anxiety and depression" (Pearlin et al., 1988, p.510). Attendant life strains yield important ramifications for care providers of people with AIDS.

There are many obvious stresses directly involved in caring for someone who is HIV-positive. Coordinating care for PLWHA, monitoring and managing symptomatology throughout the course of the illness, and answering to various employment, social and household demands are just a few of many.

Conflict and uncertainty are also major sources of stress for caregivers. Reynolds and Alonzo (1998) report their sample of partners and family members of people living with HIV "described considerable conflict over how to prioritize competing demands, or accommodate unwelcome changes in expectations for relationships, lifestyle, work and finances" (p.255). Conflict can result for a variety of reasons. Conflicts between work demands or care-related demands, and between disclosing serostatus or remaining silent, cause considerable stress to caregivers of PLWHA.

The significance of uncertainty is documented by a number of researchers. Moynihan et al. (1988) state that the uncertainties related to this disease are stressful. Brown and Powell-Cope note that uncertainty is a basic social-psychological problem in the AIDS caregiving transition. Stujduhar and Davies (1998) explain that "feelings of uncertainty pervaded the lives of caregivers and arose from the perpetual and unpredictable changes accompanying HIV/AIDS" (p.17). The unpredictable and often volatile nature of AIDS makes uncertainty synonymous with caregiving.

Brown and Powell-Cope (1991) utilize qualitative methods to identify a variety of factors related to uncertainty for family care providers of people living with AIDS. These authors note "much of the uncertainty in the family caregiving literature was associated with the illness itself, whereas data in the present study revealed that uncertainty in AIDS caregiving also pertained to loss and dying, interpersonal relationships, contagion, and the presentation of self" (Brown & Powell-Cope, 1991, p.344). Participants in their study offered the roller coaster metaphor to describe the constant changes inherent in AIDS caregiving, and the relentlessness and lack of control this role implies (Brown & Powell-Cope, 1991). Thus both the disease itself, and the variety of factors related to the disease cause uncertainty.

Three major sources of uncertainty related to the care recipient are identified as: 1) whether to remain hopeful about the PWA's survival; 2) not knowing which illness or opportunistic infection would herald the PWA's death; or 3) not knowing when the death would occur (Brown & Powell-Cope, 1991). The nature of AIDS implies years of such sources of uncertainty. Folkman (1997) concludes that there are two psychologically stressing components of the disease: the situation is uncontrollable (the caregiver can do little to control the progression of the disease, and the ill person will ultimately die); and the situation is not static (the recipient's disease progresses over time). Both of these authors confirm that uncertainty is rooted in the nature of the progression of AIDS, and the seemingly inevitable death of the care-recipient.

Health care providers represent medical advice and care for the recipient and education and support for the care provider. Yet, health care providers can also be major sources of uncertainty for caregivers. Caregivers often ask questions of health care providers, and are disappointed to discover that health care providers are equally as uncertain (Brown & Powell-Cope, 1991). Having unanswered questions about care is a significant source of anxiety. This could be confounded by the fact that caregivers may view health care providers as their only source of support and assistance in terms of caring for the recipient.

Financial strain is also a particularly important root of uncertainty. When a household depends on the income of the HIV-positive individual, his or her inability to continue working can create a substantial financial strain (Reynolds & Alonzo, 1998). Finally, there are issues related to the gay community that are significant sources of stress. One source of uncertainty for gay and bisexual male caregivers derives from being part of group at high risk for AIDS (Turner et al., 1994).

Family disapproval of the care-recipient and caregivers' lifestyle can cause great anxiety. Caregivers in the gay community may be the target of regrets and recriminations of the family, regarding the care-recipient's homosexuality or lifestyle (Pearlin et al., 1988). Over and above all of the complications and stresses caused by this virus, caregivers face disapproval from family and friends. LeBlanc et al. (1997) write that AIDS caregivers are likely to face additional stressors due to the problematic nature of social responses to the epidemic. The stress-related ramifications of AIDS are clearly pertinent to the quality of life of the care provider.

The concept of burden is detailed at great length in caregiver studies for non-HIV/AIDS conditions and diseases. The significance of how caregivers feel about, and respond to their role makes this concept worthy of further exploration. In relation to AIDS caregiving, burden is described as "the physical, emotional, instrumental and social problems associated with caregiving" (Pakenham et al., 1995, p.189).

Care providers experience burden when they perceive that caregiving has interfered with their pursuit of important goals and role functioning (Rosengard & Folkman, 1997). Care providers feel supported to the extent that they perceive availability and adequacy of social support in material, emotional and practical areas (Rosengard & Folkman, 1997). As the burden or inability to be resilient increases, the well being of the care provider decreases (Tebb, 1995). Thus, caregivers that feel burdened by assuming the caregiving role experience a diminished sense of well being. Tebb (1995) cautions, "How people define and address their well-being and distress greatly affects their ability to meet their own basic needs" (p.88).

In a study of caregiving partners of men with AIDS, Rosengard and Folkman (1997) found high suicidal ideators (those having suicidal ideation) were characterized by feeling burdened by caregiving. Therefore, burden is undeniably important to the life quality of the caregiver. The burden of AIDS can seem insurmountable: caregivers may wish for their loved one to die, to diminish their own anguish or to stop an over-extended commitment to a sick and/or dependent AIDS relative (Lippmann et al., 1993).

Pakenham et al. (1995) speculate that the stage of a patient's illness (whether he/she is HIV asymptomatic or symptomatic) is an important variable that might influence the care provider's level of burden and adjustment. Reynolds and Alonzo (1998) also note that caregivers may experience greater burdens of caring as the ill person's dependencies increase. These conclusions are supported by the premise that caregivers report the greatest burden in the area of interpersonal care (Clipp et al., 1995). Specifically, caregivers of PLWHA in one study indicated that the task of providing emotional support to their loved ones was the most difficult and demanding aspect of their work (Clipp et al., 1995). Thus, burden is related to an individual's perception of their own capacity and ability to continue to provide support and care to a person with HIV or AIDS.

Death and Dying

For care providers of people with HIV or AIDS, issues surrounding death and dying are paramount. Dealing with death is an obvious and resultant experience of caregiving for people who are HIV positive (Wade & Perlman Simon, 1993). The nature of the inevitable conclusion to the caregiving process makes providing care to PLWHA particularly difficult. Caregivers experience significant, multiple losses, as they watch their loved one's physical appearance, stamina, memory, and coordination, decline (Walker et al., 1996). Reynolds and Alonzo (1998) explain that sometimes caregivers also take on the responsibility to "find ways to help their partner accept death" (p.256). Thus, in addition to coming to terms with the disease themselves, caregivers assume the responsibility to help the care-recipient accept their fate.

For parental caregivers unique death and dying issues surface. O'Donnell & Bernier (1990) explain "watching one's child die of AIDS is particularly hard, in part because it is against the natural order of the life cycle, where parents are expected to die before their children" (p.16). Because caregiving can be a lengthy process, during this time caregivers may experience the losses of various individuals within their personal network as well. The result of this sequence of losses can be devastating: "The proliferation of AIDS, coupled with the attenuation of informal networks, leaves the caregiver in a profound state of anticipatory isolation" (Pearlin et al., 1988, p.509). Gay men, in particular, appear likely to suffer multiple losses, which "is a strong predictor of symptom and behaviors associated with serious psychological distress among gay men" (Martin, 1988, p.860).

Walker et al. (1996) advocate for intervening with caregivers during the time of anticipatory grief (the length of time between the diagnosis of a terminal illness and the death of the individual). These authors note that multiple losses may complicate the process, because the griever moves erratically through the grieving stages for a number of people who have died, never successfully completing the process associated with one loss before another occurs (Walker et al., 1996). Issues surrounding death and dying weigh heavily on AIDS informal caregivers.

Reciprocity and Sexuality

The concept of reciprocity is significant in AIDS caregiving, but is not often acknowledged in the literature. Existing evidence suggests that because "caring takes place within a context of a close relationship, there is an interdependence between the carer and the person with a disability or illness" (Schofield et al., 1996, p.161). In an Australian study by Pakenham et al. (1995) care providers of people with HIV and patients were interviewed about carer burden and adjustment to caregiving. These researchers report there were "moderately high correlations between patients' and carers' levels of adjustment (within caring dyads), indicating that both patient and carer cope well together or have many problems together" (p.198).

Using a systems perspective, Kaminsky, Kurtines, Hervis, Blaney, Millon & Szapocsnik (1990) explain that an interdependency exists between the HIV-infected person and those who comprise his or her significant and immediate psychosocial context. Reciprocity is an important concept, as it illustrates the intensely interconnected relationship between the caregiver and the care receiver. It implies that aspects related to caregiving for an HIV-positive individual impact the caregiver.

Many types of relationships exist between care provider and recipient in AIDS caring. Caregivers of HIV-positive people that are also partners of the care-recipient deal with issues surrounding intimacy and sexuality with their partner, adding to the stress of their caregiving role. Moynihan et al. (1988) explain "the fear of additional exposure to the disease and the desire to protect each other can greatly inhibit physical intimacy, which is a major source of comfort for most terminally ill people" (p.382). Lippmann et al. (1993) note that the couple is doubly affected sexually by the virus, as further intimacy creates new potential dangers.

Questions about termination or the continuation of the relationship and worries about contagion and abandonment are implications of the disease for partners (Lippmann et al., 1993). Indeed, "Sexuality is central to the consideration of the role of HIV in quality of life" (Ross & Ryan, 1995, p.1). Fear of transmission of the AIDS virus is not limited to a sexual relationship with a care recipient.

Psychological and Physical Connections in the Caregiving Experience

Individual serostatus, dangers of viral transmission, and the physical toll of providing care encompass the physical factors related to caregiving. Each of these factors is related to the physical health status of the caregiver, but is also inextricably interconnected with psychological aspects of the individual. To explain the physical ramifications of caregiving, a discussion of the psychological impact must coincide.

Two noted characteristics that are of particular significance to caregivers of people with AIDS are 1) the caregivers' own HIV status and 2) the caregivers' perceptions of personal vulnerability to AIDS (Turner et al., 1994). There are a variety of reasons why serostatus is significant. HIV-positive caregivers of people with symptomatic HIV or full-blown AIDS are forced to deal with the reality that they may be in the same position in the future. Hansell, Hughes, Caliandro, Russo, Budin, Hartman and Hernandez (1998) have reported that for seropositive caregivers, HIV/AIDS is both a personal health crisis and a caregiver crisis. Seropositive caregivers are plagued with a more complex situation (Hansell et al., 1998).

Many seropositive people begin to lose hope, as they are forced to watch their loved ones go through the difficult end stages of AIDS and die (Moynihan et al., 1988). Identification with this disease increases the burden for the caregiver, as they are confronted with their vulnerability to disease and death. The consequence of this confrontation is that "when death is brought home, literally, to the caregiver, depression and anxiety are virtually inescapable" (Pearlin et al., 1988, p.508). Identification with the care recipient by way of serostatus makes AIDS care provision unique (Pearlin et al., 1988).

It is noted that "anxiety and depression are higher in individuals who are seropositive than they are in persons who have been formally diagnosed with AIDS because seropositive individuals must live with greater ambiguity and uncertainty about their future" (Moynihan et al., 1988, p.380). Issues of uncertainty pervade for seropositive caregivers. A care provider may be caught in a position of fear about his or her own future on one hand, and guilt over his or her present advantage in health on the other (Pearlin et al., 1988). Caregivers will themselves eventually face ill health and the dilemma of alternating between offering support and needing it (McCann & Wadsworth, 1992). Clearly, "Today's caregiver may see himself as tomorrow's patient – but a patient without the benefit of care from a loved one" (Pearlin et al., 1988, p.509).

Perceptions of personal vulnerability to the disease can pose substantial challenges to caregivers of PLWHA. Apart from other psychological and physical strains associated with HIV caregiving, caregivers risk their own exposure to the disease by providing care, which can be a substantial source of anxiety (Reynolds & Alonzo, 1998; Pakenham et al., 1995). For individuals who are unaware of their serostatus, uncertainty about transmission of the virus is identified as particularly troubling in the beginning of caregiving (Brown & Powell-Cope, 1991). Caregivers who perceive risk of contagion carry an additional burden of caregiving. In terms of appraisal of the stress, threat and benefit of caregiving, "...the lovers/friends of AIDS patients who perceive themselves to be members of HIV risk groups are caregivers who perceive the greatest magnitude of threat related to caregiving" (Clipp et al., 1995, p.17).

Serostatus is an important factor in physical health of the caregiver: seronegative caregivers (caregivers who are HIV-negative) experience fewer symptoms of poor physical health than their seropositive (HIV-positive) counterparts (LeBlanc et al., 1997). This conclusion is expected when one considers the nature of the virus. LeBlanc et al. (1997) note "not only are large numbers of these caregivers experiencing a deterioration in their own health due to HIV and AIDS, their roles as caregivers exacerbate their health problems, and consequently their ability to endure as care providers" (p.922).

Regardless of serostatus, over time, caregivers' physical reserves are threatened by the increasing demands of the physical care of the recipient. The nature of the AIDS virus often necessitates erratic and intense caregiving responsibilities. McDonell, Abell and Miller (1991) report that chronic fatigue, physical exhaustion, and the deterioration of the caregivers own health are all possible consequences of caring for someone with AIDS.

HIV-positive caregivers of children with AIDS in one study confessed that they neglected their own health due to a preoccupation with their children's health care, and said they believed they were neglecting their child's health by caring for themselves (Crandles, Sussman, Berthaud & Sunderland, 1992). The practice of constant caregiving exacts a hefty toll on care providers. Pakenham et al. (1995) conclude that caregivers living with a patient experienced markedly more burden than those who did not live with the patient. The physical impact of caregiving is detrimental to the care provider for a variety of reasons, and in a variety of ways.

Economic Impact of Caring

In economic terms, caregivers are clearly an invaluable resource. An assumption is often made that the care provided to PLWHA is a social, not also an economic contribution (Ward & Brown, 1994). Caregivers provide care to HIV-positive people usually with minimal, or no assistance from formal institutions. Unfortunately for caregivers, the actions of formal institutions indicate that "carers are perceived as an invisible yet free resource and that there is little concern for the well being of carers as such" (Schofield et al., 1996, p.159).

LeBlanc et al. (1997) report

> ...any cost-savings to our formal health care system's response to AIDS that we may attribute to the presence of informal caregivers is probably over-estimated in that they do not take into account increases in the needs and service use of caregivers who are struggling to maintain their own emotional and physical health (p.922).

These formulas also fail to consider the costs directly related to providing care to the PLWHA, such as provision of transportation, rent, food, or medications.

Using a market valuation method, the annual value of unpaid care, including housework, for one PLWHA was calculated to be $25,857.88 in an American study of labour and cost in caregiving (Ward & Brown, 1994). This estimate seems conservative. These care providers spent an average of five hours per week on housework for a PLWHA, and 8.5 hours a day performing personal care tasks for the PLWHA.

Caregivers often lack the financial resources to provide care (Turner et al., 1994), and caregiving can impact on the person's actual or potential income at the peak of their productive lives (Bowie, Tobias & Williams, 1996). Indeed, Park and Folkman (1997) explain that care providers deal "with caregiving and bereavement at a stage in life when most people are building relationships and establishing themselves in jobs and careers" (p.424).

New Zealand authors Bowie et al. (1996) focus on the private costs (cost incurred by people with AIDS and their caregivers) in a rare article about AIDS and microeconomics for caregivers of PLWHA. This article is limited by an unrepresentative sample, but nevertheless illustrates the burdens placed on caregivers by both direct and indirect costs associated with caregiving. They note "Alternative uses always exist for private resources implying that sacrifices must be made; opportunity costs are, as always, inevitable" (Bowie et al., 1996, p.51). Some of the participants in this study attributed a reduced income or potential income to their caregiving role, and there was a general deterioration in quality of life for this sample population. While it has been established that caregivers of people with AIDS occupy a variety of economic backgrounds, Turner et al. (1994) report that minorities and those with the poorest financial resources are more likely to perform the most labor intensive caregiving tasks.

For the HIV-positive parental caregiver, Reidy et al. (1991) explain,

> ...she faces loss of income for time taken from work for treatment or diagnosis...she faces eventual loss of employment and the need for financial assistance in the form of welfare. Further, with time, the demands of the child's and her own condition, will increase as her human and financial resources decrease (p.334).

This reinforces the notion that much of the expenses to caregivers represent opportunity costs (Turner et al., 1994). Caregivers of children express instrumental needs related to caring for an HIV-positive child: aid with household tasks, transport for their children for their consultations at the hospital, help in writing letters and paying bills, and monetary aide (Reidy et al., 1991). Economics and caregiving are inextricably connected.

Economic issues may emerge for the caregiver in the career world itself. Pearlin et al. (1988) note:

> ...caregivers report a loss of concentration on the job; they begin to lack the stamina and strength required by the work; they engage in more absenteeism; and they evaluate their own work performance as being subpar. The lowered quality of work, in turn, can induce a sense of inadequacy, diminish self-esteem, and threaten job security (p.511).

Clearly, in terms of the economic impact of caregiving, quality of life can be affected by caring for someone with HIV/AIDS. Considering the potential psychological, social, physical and financial stresses of caring for someone with HIV or AIDS, a discussion about support is necessarily warranted. The following section illustrates the importance, and often lack of, support available to care providers of PLWHA.

The Significance of Support

Informal care has emerged due to spiralling costs for in-patient care, advances in treatments and the acceptance that most people would prefer to be cared for at home (Beedham and Wilson-Barnett, 1993). Yet, despite this emergence, caregivers lack support with their substantial tasks related to care. In a United Kingdom study of informal care providers of PLWHA by McCann and Wadsworth (1992), caregivers identified areas where additional assistance was needed. This included emotional support, help with specific practical tasks and ways of maintaining work outside of the home. These authors, however, also found a disparity between people's recognition of a need for assistance, and their willingness to ask for it (McCann & Wadsworth, 1992). Indeed, caregivers explained they often did not know where to go for help, or were too busy or tired to obtain it (McCann & Wadsworth, 1992).

With the potentially enormous demands placed upon caregivers (Beedham & Wilson-Barnett, 1993), many psychological stresses emerge. Support plays a substantial role for caregivers. Turner et al. (1998) speculate that caregivers with higher levels of social support may be less likely to experience negative outcomes. In addition, Studuhar and Davies (1998) report that the nature of support care providers receive greatly influences their ability to implement caregiving strategies. Caregiving strategies provide opportunities for caregivers to proactively exercise control over their present circumstances. Nevertheless, Stujduhar and Davies (1998) note, "...the feeling that 'nobody understands' permeated the lives of many caregivers" (p.19).

The health care and social services offered to caregivers of people with AIDS are important, as formal sources of support are often the only types available to caregivers of PLWHA. Pakenham, Dadds and Terry (1995) note that "most of the services that provide assistance for carers are directed towards the terminal end of the disease continuum, whereas less support is provided to carers of asymptomatic persons" (p.201). Stujduhar and Davies (1998) concur: in most instances caregivers experience problems accessing services when they need them the most.

Caregivers voice complaints about the social service system, noting feelings of humiliation resulting from having to constantly ask for money to pay for necessities such as medications, dental work, and basic living expenses (Stujduhar & Davies, 1998). Problems with formal institutions cause additional stress to caregivers that are already burdened. Stujduhar and Davies (1998) state "Problems in obtaining financial assistance meant expending time and energy to advocate and lobby on behalf of their loved one" (p.19). Time and energy are two resources ritualistically depleted by care providers.

The health care system in particular, is recognized as an important variable of support. Stujduhar and Davies (1998) report "Caregivers repeatedly talked about the rigid, impersonal, and demeaning systems that disregarded and diminished their experience and left little room for individualized, consistent, and compassionate care" (p.19). Caregivers also cite unsupportive interactions with health-care providers as significant (Stujduhar, 1997). Encounters with health-care providers can leave care providers "feeling angry, bitter, isolated, and disillusioned" (Stujduhar, 1997, p.80). Caregivers in a study by Stujduhar and Davies (1998) "...found it difficult to work as a team when others, specifically health care providers, had difficulty relinquishing control and engaging in participatory care" (p.18). Moreover, caregivers "felt they were often not heard and had to work even harder to obtain comfort for their loved one" (Stujduhar & Davies, 1998, p.18). Support is an important component of care provision, and the availability and maintenance of supportive networks may encourage positive assessments of the caregiving experience.

Deriving Positive Experiences from Caring

Considering the key role care providers play in the lives of people with HIV and AIDS, and the potential stresses involved, is it possible to derive meaning and positive experiences from caring? Despite the multitude of struggles that care providers endure while caring for HIV-positive individuals, positive aspects are often derived from taking on this responsibility. Care providers cite improved relationships with care recipients, for instance, including more honest communication and closeness between them (Wardlaw, 1994).

Caregivers may find providing care to be more valuable over time with an increased sense of mastery. Reynolds and Alonzo (1998) report that several caregivers in their study "described that they developed an increased sense of confidence in their ability to manage difficult and unpredictable aspects of the illness and their care experience" (p.257). These authors continue by stating "in the most fortunate caregiving situations, the caregivers realized a role and identity that they found extremely meaningful" (p.257). Caregivers discover methods to enhance positive feelings in their lives. Folkman (1997) reports that caregivers identify realistic, attainable goals by focusing on specific, proximal tasks or problems related to caregiving. Such positive events for the caregiver may provide respite, and help restore self-esteem, hope and perceived social support (Folkman, 1997).

Caregivers learn to live and view their worlds differently through the care provision process (Brown & Powell-Cope, 1991). Many caregivers, between AIDS-related crises, focus more on their own lives, create a more peaceful existence, and increase their involvement in community and social activities (Brown & Powell-Cope, 1991; Reynolds & Alonzo, 1998). Feeling useful, compassionate, and fulfilled can result from caring, and despite many taxing activities, finding clarity, strength and courage is possible (Wardlaw, 1994). Folkman (1997) notes that "despite high levels of distress, people also experience positive psychological states during caregiving. Moreover, these states are not only possible, but common" (p.1207).

Clipp et al. (1995) also note that care providers of PLWHA in their sample reported significantly higher benefit appraisals than appraisals of stress or threat. According to these authors, for the majority of caregivers, providing care to persons with AIDS is a positive experience. Interestingly, these appraisals tend to come from caregivers whose loved ones are among the sickest in the sample and who were blood relatives of the patient.

Crandles et al. (1992) explain that caregivers of children with HIV "believe they can have hope and happiness despite the impact that HIV has on their lives" (p.350). The negative psychological states associated with significant and enduring stress may actually motivate caregivers – consciously or unconsciously – to search for and create positive psychological states in order to gain relief from the distress of this task (Folkman, 1997). Indeed, many care providers express philosophical and spiritual transformations through this process (Wardlaw, 1994).

Summary

This chapter provided an overview of the existing literature about care providers in general terms, followed by an introduction to the issues for caregivers of people living with HIV or AIDS. The literature indicates that caregiver quality of life is challenged by a multitude of significant issues and responsibilities. A description of the tasks and characteristics of caregivers was followed by a discussion about volunteerism and family caring. The stigma associated with AIDS and the intensity of care for a PLWHA were described. Various psychological and social consequences were discussed, in particular stressors and burden and death and dying. A discussion about the concepts of reciprocity and sexuality in the context of caregiving for someone with HIV or AIDS was followed by the physical and economic implications of caring. Finally, the significance of support and the positive aspects that can be derived from caregiving were explained. Chapter Three describes the many definitions and facets of quality of life, and discusses the subjective and objective components and measures in quality of life studies.

Chapter Three: Quality of Life

Introduction

The intentions of this chapter are to introduce the concept of quality of life (QOL), and to discuss areas of consensus and disagreement within this field of study. An explanation of the origin of QOL studies is followed by a brief discussion about defining quality of life. The World Health Organization's definitions of health and quality of life are then presented. Several quality of life domains may be studied in QOL research, and these are described. The chapter is concluded with a discussion about subjective and objective components and measures in quality of life studies.

Quality of Life as a Concept

Quality of life (QOL) is potentially one of the most misunderstood and debated terms used by the public and researchers in a variety of disciplines. Many questions surface with respect to quality of life. How is quality of life conceptualized? How is QOL defined? What methods are used to evaluate quality of life? The conceptualization, definitions utilized, and evaluation of quality of life differ by instrument, discipline and purpose of study.. Such diversity in quality of life studies is extensive; consensus has not been reached among researchers on any aspect of quality of life. Indeed, disagreement appears inherent to the QOL concept. Yet, the prominent misconception that quality of life is a universally understood phenomenon remains.

Quality of life is frequently referenced by researchers and has various applications. A discussion about the meanings associated with quality of life illustrates the complexity of this concept. The word *quality*, according to Szalai (1980) refers to "the more or less 'good' or 'satisfactory' character of people's life" (p.8). The term quality of life overlaps but is not synonymous with a number of other terms, including "social indicators", "level of living" and "way of life" (Szalai, 1980, p.9). Quality of life is associated with terms such as happiness, conditions of living and life satisfaction (Meeberg, 1993).

As mentioned, quality of life is not synonymous with these terms. It should be noted that QOL and life satisfaction differ, in that QOL is a broader and more encompassing term (Meeberg, 1993), and that satisfaction results from quality of life (Meeberg, 1993). Thus, life satisfaction may be considered a consequence of QOL, like happiness, rather than an equivalent term. Such a debate over associated terms illustrates the complexity of the quality of life concept. Interestingly, although researchers often agree about what QOL does *not* include, one encompassing and universal definition of what quality of life does include has not been established. The inability to establish a definition of quality of life may be due in part to the relatively new emergence of the QOL concept in the literature.

The Origin of Quality of Life Studies

The term quality of life did not emerge until the latter half of the 20th century. The term quality of life was originally coined in the post-war period to describe the effect of material affluence on people's lives. QOL was subsequently broadened to include education, health and welfare, and economic and industrial growth (Carr, Thompson & Kirwan, 1996). Since the initial emergence of this term, quality of life adopted new emphases and connotations. Over the past twenty years in particular, a plethora of quality of life studies appeared. In the literature of the past two decades, the term quality of life is often found in terms of health-related quality of life. A trend that encouraged this development is a change in lay and professional attitudes toward including the patient as a focus of medical care (Carr et al., 1996).

General QOL differs from health-related QOL in that it includes an individual's evaluation of all aspects of life (Bonomi, Patrick, Bushnell & Martin, 2000). Health-related quality of life is often used to indicate quality of life as it relates to illnesses, diseases or treatments people experience (Bonomi et al., 2000). The World Health Organization Quality of Life Group explains "The general concept of quality of life was initially considered a useful adjunct to traditional concepts of health and functional status" (The WHOQOL Group, 1998, p.1569). Indeed, early attempts at assessments merely examined functional status, rather than the broader concept of quality of life (The WHOQOL Group, 1998). Simply noting side effects of treatments was put forward as a QOL assessment (Orley, Saxena & Herrman, 1998). Presently, many general quality of life studies are emerging, as a result of a shift away from specifically health-related measures. For purposes of this thesis, general quality of life will be the focus. How general quality of life is defined is another important point of discussion.

Defining Quality of Life

What is quality of life? That "quality of life" itself evades definition is an indication of the complexity of this field of study. Ryan (1995) states:

> Currently the field of quality of life, if a distinct field can be said to exist, is beset with conceptual and methodological problems, not the least of those relating to

> definitional and operational concerns – what is the definition of quality of life and how can it be operationalized to yield reliable and valid data? (p.148).

Researchers define QOL according to individual preferences and purposes. Thus, results from one study cannot be generalized to other QOL studies, as they are confined to individual definitions of quality of life. Ironically, a number of researchers using the term quality of life neglect to define its meaning at all! Indeed, when the basis for study is ambiguous, research to investigate QOL is difficult (Meeberg, 1993).

Quality of life studies remain limited despite many years of research devoted to this domain of study. QOL research is of significant consideration for society in general (Meeberg, 1993), yet is not a concrete, clearly defined area of research. Burgess and Catalan (1991) note "Quality of life is an umbrella term for a multidimensional and multifaceted construct whose parameters are neither clearly defined nor limited by conventional usage" (p.363). Szabo (On Behalf of the WHOQOL Group) (1996) indicates,

> Both within each cultural setting and between cultural settings quality of life cannot be easily described in terms of one or several words or phrases, but instead it is the breadth and content of quality of life issues that define it (p.356).

A range of strategies currently exists that approach the concept differently, yet a common gestalt appears to be emerging slowly (Schipper, Clinch & Olweny, 1996). According to Schipper et al. (1996), four properties of the quality of life concept include "it is multifactorial, it is patient self-administered, its value is variable over time, and it is subjective" (p.18). The following section illustrates the practical application of many elements of the quality of life concept through a description of the World Health Organization's definitions of health and quality of life.

World Health Organization and Quality of Life

Health, according to the Constitution of the World Health Organization (WHO) "…is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2000). The WHO definition, although criticized by some, is the most frequently cited and widely recognized definition of health. WHO employs an encompassing approach to health, as health is defined in terms of well being, rather than simply the presence or absence of illness. Yet, the definition is limited in that it only considers three domains (physical, mental and social). It follows from this definition, that measurement of health must go beyond the traditional measures of sickness, pain or disability, and examine other aspects of health. Indeed the assessment by WHO of overall QOL of the individual goes beyond traditional measures, and considers many domains, or parts, of quality of life.

Without a clear definition or a standard means of measuring quality of life, there can be little progress towards including it as an objective in the creation of a more healthy society (Orley et al., 1998). The World Health Organization defines quality of life as,

> …individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment ("Measuring Quality of Life," 1997, p.1).

This definition reflects the view of WHO that quality of life refers to a subjective evaluation, which is embedded in a cultural, social, and environmental context ("Introduction and Background," 1995).

The WHOQOL Group (1996) explains this subjective emphasis: "The definition is not concerned with objective measurement of people's condition or what they possess" (p.354). For example, "income is not a factor in either absolute or relative terms, but the degree of satisfaction which people feel about their income is taken into account" (The WHOQOL Group, 1996). According to Orley et al. (1998), QOL is an internal experience: "it is influenced by what is happening 'out there', but it is coloured by the subjects' earlier experiences, their mental state, their personality and their expectations" (p.291).

The World Health Organization quality of life definition differs from many, because it honours subjectivity, includes a broad range of criteria, and embraces positive aspects of an individual's life (The WHOQOL Group, 1996). The WHO definition states that quality of life is a broad ranging concept affected by a variety of parts, or domains, of one's life. The following section provides a description of different domains included in quality of life studies, and a discussion about the rationale for including specific domains.

Quality of Life Domains of Study

Quality of life is the sum of its component parts, or domains. Quality of life indicators generally involve "the measurement of the relative degree of satisfaction or dissatisfaction an individual receives from a particular domain" (Harvey, 1980, p.14).

There are debates, however, about the appropriate domains to include in QOL research. Burgess and Catalan (1991) aptly state "The physical domain is the most commonly assessed area of quality of life" (p.358). Considering the health-related focus of a number of quality of life studies, this is probable. Other researchers conclude there are three basic domains commonly cited to assess quality of life: physical, social and psychological (Ryan, 1995; The WHOQOL Group, 1995).

The concept of QOL is approached from many perspectives, including physical well being, the spiritual and psychological perspectives, and the social, economic, and political (Schipper et al., 1996). Income (Friedland et al., 1996), living conditions (Li, Young, Wei, Zheng, Xiao, Wang & Chen, 1998), health status, job satisfaction, and living standards (Meeberg, 1993) are also cited as appropriate domains for study. The World Health Organization Quality of Life Group (1996) defines six domains: physical, psychological, level of independence, social relationships, environmental factors and spirituality/religion/personal beliefs.

According to Spilker (1996) "Because of the intimate connection between social relationships and health (as defined by the WHO) and also between spirituality and health, all domains should be assessed when health-related quality of life is measured". This declaration can be extrapolated further to assert that all domains should be included when general quality of life is measured as well. Because such intimate connections exist between domains related to health, it is reasonable to assume that intimate connections also exist between other domains in one's life. An examination that fails to investigate several domains of one's life cannot offer an encompassing assessment of one's quality of life.

In addition to the actual domains present in an assessment, it is worth noting that what is examined within these domains is also significant. The information gathered about items, or facets, within domains varies from study to study. Researchers striving for a more holistic assessment advocate for an in-depth examination of particular facets. For example, Burgess and Catalan (1991) explain "Within the chosen period of enquiry, not only should the presence or absence of a particular aspect of quality of life be addressed, but it may also be useful to know about the frequency, the intensity, and the duration" (p.359). In the burgeoning field of subjective measures, such considerations are constructive. The subjectivity inherent in quality of life studies is undoubtedly a key feature of this research area. The preceding section describes subjective and objective measures, and the debate surrounding both approaches.

Subjectivity versus Objectivity

There is a substantial debate among researchers about the utilization of objective and subjective components in quality of life research. Subjective measures of quality of life include questions about attitudes and perceptions, while objective measures focus on the functional status of an individual (Grimes & Cole, 1996). Li et al. (1998) explain that a purely objective approach, such as a measure of physical function status cannot be used to assess feelings and concerns about QOL for a particular person. Nor do objective measures account for subcultural differences in perceptions of QOL. Even when a certain group shares the same culture, individuals can have widely varying personal beliefs, values, goals, and needs (Li et al., 1998).

Although many researchers argue QOL must be strictly objective or subjective, quality of life can be viewed as either subjective, objective, or both (Meeberg, 1993). Those researchers subscribing to the objective protocol argue that subjective measures are not concrete, cannot be measured properly and are not tangible. According to Schipper et al. (1996) "the confusion comes in the assumption that something subjective cannot be measured appropriately, and hence cannot compete with the validity of physical measurements" (p.15). Contrary to those who argue that subjective measurements of quality of life are unreliable, Burgess and Catalan (1991) note "Subjective measures can be psychometrically sound" (p.358).

The utilization of subjective, self-perceived and self-reported assessments in QOL research is a clear departure from other fields of research. Grimes and Cole (1996) report "while there is general agreement that high quality of a person's life is a desired outcome, there is less agreement on the measurement of this concept" (p.692). Past attempts to define and describe quality of life were commonly objective in nature, yet, "more recently, the emphasis has been focused on the subjective evaluation of quality of life" (Burgess & Catalan, 1991, p.358). Indeed, there is a growing recognition that QOL is inherently subjective and cannot be observed by others, as walking speed, or the occurrence of vomiting can (Bonomi et al., 2000).

Historically, the medical model has employed objective instruments to measure quality of life. Utilizing purely objective measures, however, is limiting. Quality of life is traditionally measured "based on scales which have been biased toward functioning as measured by the physician or have concentrated on physical function" (Ross & Ryan, 1995, p.8). Particular objective measures, such as functional scales, are criticized because "functional scales, although logically related to disease pathology, progression and symptomatology, may be conceptually different from one's perceptions of well-being" (Grimes & Cole, 1996, p.692). Such criticisms are well founded: assessing QOL based solely on a particular facet of the physical domain is flawed.

There is a cross-cultural benefit to subjective quality of life measures as well. Utilizing an instrument that examines people's degree of satisfaction with an aspect of their lives, rather than examining the actual aspect by external "objective" benchmarks, makes subjective instruments more feasible internationally comparable instruments (Orley et al., 1998). Subjective evaluation permits international/cultural comparisons, because actual aspects vary greatly from culture to culture. For example, it is more descriptive and reasonable to compare people's degree of satisfaction with their living space, than to compare the actual living space of a psychiatrist in New York to the actual living space of a pavement dweller in Calcutta (Orley et al., 1998).

Many researchers advocate for a combination of objective and subjective measures. Szalai (1980) argues that the objective facts or factors of one's life and the subjective perception and assessment one has of these factors of life and oneself are both relevant. Certainly, both are worthy of exploration. Meeberg (1993) explains, "The subjective aspect is essential because a sense of personal satisfaction is intrinsic to QOL. The objective component is also necessary" (p.37). Quality of life studies utilizing only subjective criteria or a combination of subjective and objective criteria are emerging rapidly, and add to a unique field of studies related to life quality. The following section describes the quality of life framework selected for this thesis, which will be used as a reference point from which to think about this study and its results.

Quality of Life Framework

A number of conceptual frameworks exist to describe and explain quality of life. An appropriate framework provides the reader with a structure or skeleton, from which to understand a concept, and to convey results. The Centre for Health Promotion at the University of Toronto (Rootman, Raphael, Shewchuk, Renwick, Friefeld, Garber, Talbot, Woodill and Brown, 1992) developed a conceptual framework which is "unique in its comprehensiveness, universality, philosophical foundation, and practicality" (p.119). A general overview and an exploration into the various components of the framework are provided in the following sections.

Development of the QOL Framework

The framework was developed through a number of sources. Researchers examined literature from quality of life and related fields (Rootman & Raeburn, 1998). Information was also utilized from a series of focus groups that included people with developmental disabilities, their families and caregivers, and focus groups with policy makers (Rootman & Raeburn, 1998). Discussions were held with researchers of developmental disabilities as well (Rootman & Raeburn, 1998). Finally, the backgrounds and experiences of the multi-disciplinary team that developed the framework were incorporated, including the areas of sociology, psychology, rehabilitation medicine, family medicine and education (Rootman & Raeburn, 1998).

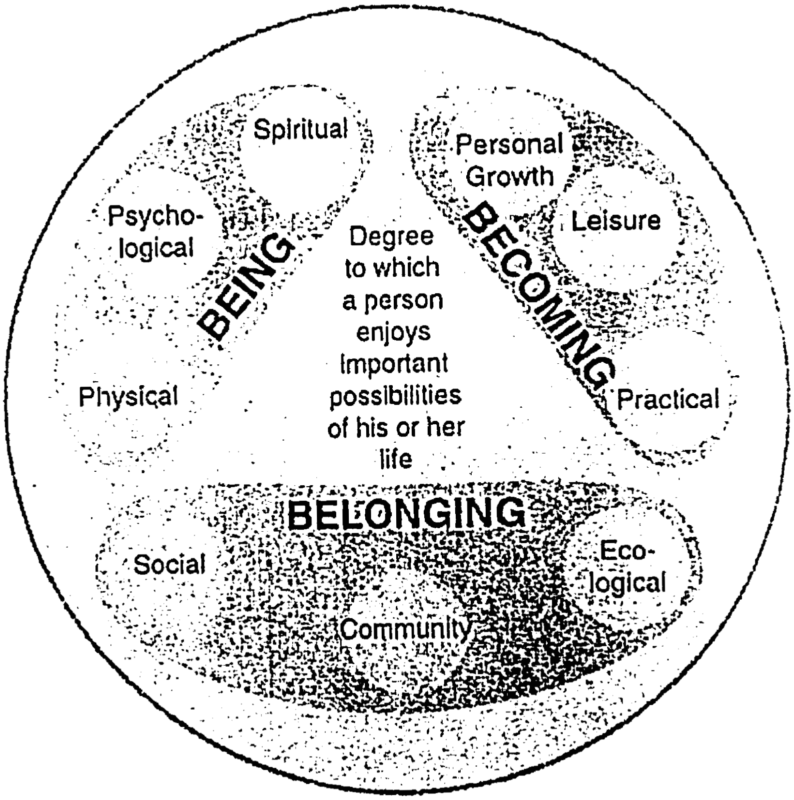
Definition of Quality of Life

The definition of quality of life, according to Rootman and Raeburn (1998), is the heart of the framework (Figure 3.1). The definition of quality of life in this framework is the "degree to which a person enjoys the important possibilities of his/her life" (Rootman & Raeburn, 1998, p.119). An explanation of the component parts of this definition will clarify its meaning. Possibilities are considered both negative and positive, in that possibilities consist of both opportunities within a person's life, and constraints on a person's life (Rootman & Raeburn, 1998). Possibilities depend on the interaction between personal factors and environmental factors, and thus vary from person to person (Rootman & Raeburn, 1998).

Possibilities also depend on the interaction between chance and choice (Rootman & Raeburn, 1998). Chance factors refer to things occurring primarily outside of an individual's control (for example, genetic inheritance), while choice refers to things that are within an individual's control, and occur because of individual decisions (Rootman & Raeburn, 1998). Enjoyment has two aspects: satisfaction and attainment (Rootman & Raeburn, 1998). Both aspects are closely connected.

Figure 3.1

Quality of Life



(Rootman & Raeburn, 1998, p.120).

Rather than viewing the presence or absence of some aspect, Rootman and Raeburn (1998) explain, "quality of life can be viewed as a continuum which represents the extent or degree of something" (p.121). This represents a marked shift from the objective ideology supporting functional scales measuring the presence of something (i.e. pain). The term "important" in the definition conveys the notion that certain possibilities are more meaningful to, or are valued more, by different people (Rootman & Raeburn, 1998). This notion also indicates the subjective emphasis of the framework. To summarize the discussion of the definition of quality of life:

> ...the degree of enjoyment of an individual's important life possibilities refers to the extent of his or her attainment of meaningful things or goals that are possible in his or her life (given the attendant opportunities and constraints) as well as the pleasure or satisfaction associated with this (p.121).

Components of Quality of Life

Rootman and Raeburn (1998) explain there are three components of quality of life: *Being, Belonging, and Becoming*. *Being* "is concerned with the most basic personal aspects of "who one is" as an individual", and *Belonging* "is concerned with how well a person fits with the social, physical, and resource-related aspects of his or her various environments" (Rootman & Raeburn, 1998, p. 121). *Becoming* "is concerned with the purposeful activities the individual does to achieve his or her goals, hopes, and aspirations, both immediately and in the long-term" (Rootman & Raeburn, 1998).

Each of these components has three sub-components. *Being* includes *physical* (physical aspects of health, nutrition, physical appearance, etc.), *psychological* (mental health and adjustment, such as feelings and evaluations of self) and *spiritual* (personal values, standards, spiritual beliefs) sub-components (Rootman & Raeburn, 1998).

Belonging involves *ecological* (links with physical environment, such as school, workplace, community), *social* (bonds with social environments, sense of belonging, acceptance) and *community* (connection with resources, access to income, employment, recreation) sub-components (Rootman & Raeburn, 1998).

Finally, *Becoming* consists of *practical* (purposeful activities such as domestic chores, paid work, volunteer activities, or helping others), *leisure* (activities that promote relaxation, stress-reduction, and balance between work and play) and *personal growth* (foster the development of knowledge and skills, formal and informal education and learning) sub-components (Rootman & Raeburn, 1998).

Importance and enjoyment determine the extent of a person's quality of life in each of the areas or dimensions. Rootman and Raeburn (1998) explain that "QOL consists of the relative importance or meaning attached to each particular sub-component and the extent of the person's enjoyment with respect to each sub-component" (p.122). A positive quality of life assessment of each sub-component might be called "well-being", and a negative one "ill-being" (Rootman & Raeburn, 1998).

Quality of Life Determinants

Quality of life is the result of identifiable determinants, which are environmental or personal (Figure 3.2). Environmental determinants are subdivided into *macro environment* and *immediate environment* factors. *Macro environment* determinants are those associated with spheres of influence beyond the self (for example, environmental, economic, societal, and political). These impact on the experience of people in the community, but are somewhat beyond immediate and everyday control (Rootman & Raeburn, 1998). *Immediate environment* determinants are factors close to the everyday lives and experience of people (for example, family, neighbourhood, workplace, school, house). There is more likelihood of at least some control over immediate environment determinants, as these lie at the local level (Rootman & Raeburn, 1998).

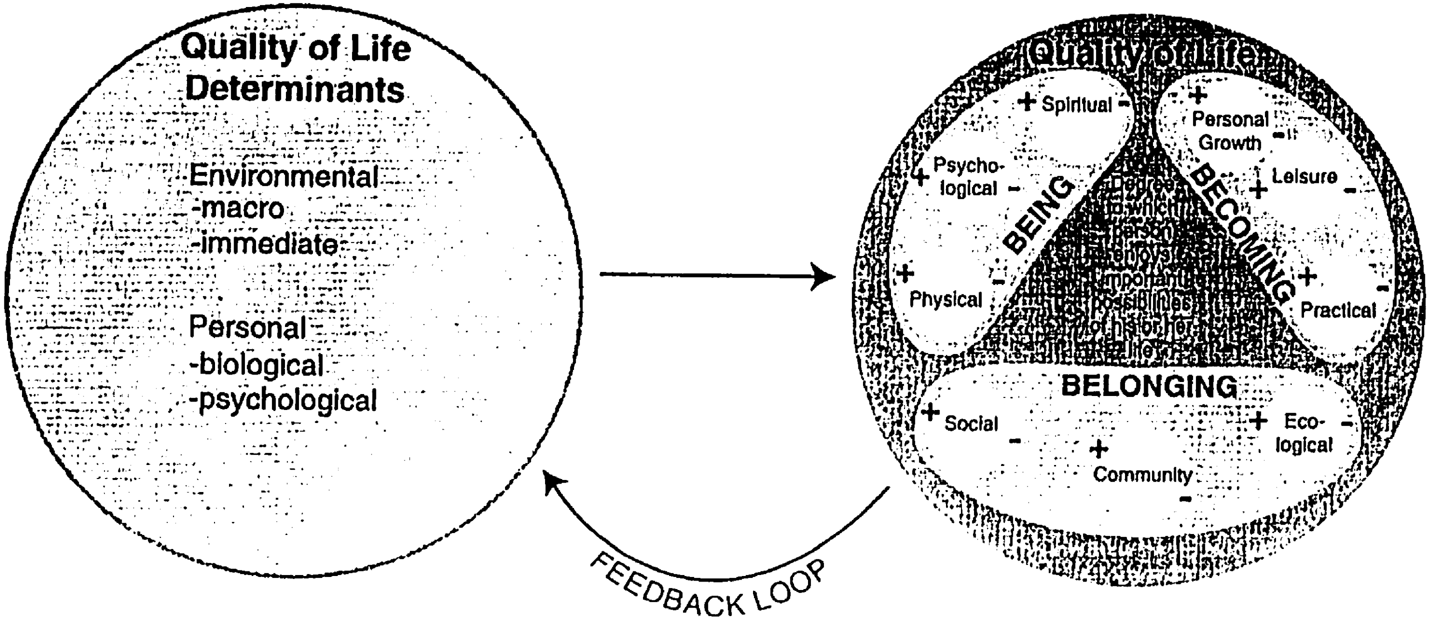
Personal determinants are subdivided into *biological* and *psychological* subcategories. *Biological* determinants are aspects of the body, brain and behaviour that are relatively unchangeable (for example, genetic inheritance, accidents) (Rootman & Raeburn, 1998). *Psychological* determinants are one's characteristic ways of dealing with the world, and which may or may not be changeable (for example, habits, cognitions, emotions, perceptions, experiences) (Rootman & Raeburn, 1998).

It is important to note that macro and immediate environmental aspects often overlap and interact, as do environmental with personal, and biological with psychological (Rootman & Raeburn, 1998). The authors recognize that this breakdown is overly simplistic. The aim with this model is not to provide an ultimate breakdown, but rather to illustrate a range of determinants with different dimensions that can broken down into manageable parts (Rootman & Raeburn, 1998).

According to this framework, a feedback loop links quality of life and the determinants of quality of life. For the simplicity of the model, QOL is expressed as an outcome, the inputs to which are a number of specific determinants (Rootman & Raeburn, 1998). The authors support the view that "everything is interconnected, and that the effect of one moment can become the cause of the next" (Rootman & Raeburn, 1998). The presence of the feedback loop illustrates this ideology.

Figure 3.2

Quality of Life Determinants



+ well-being
- ill-being

(Rootman & Raeburn, 1998, p.123).

Moderating Conditions

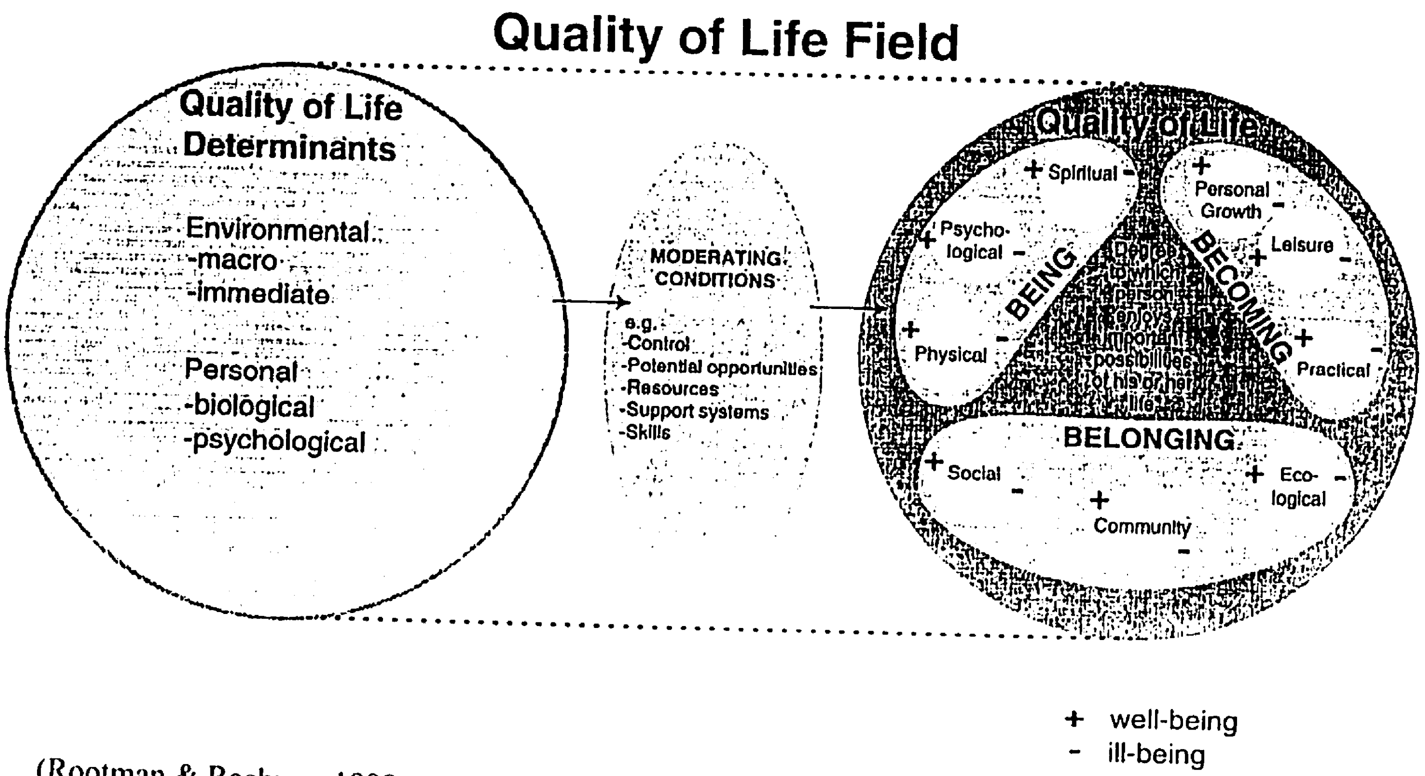
Moderating conditions is the third component of the quality of life picture (Figure 3.3). People find themselves in a set of environmental and personal determining conditions. These conditions can have negative or ill-being quality of life effects, however such negative conditions can be moderated by a number of variables (Rootman & Raeburn, 1998). These moderating conditions can be either *environmental* (i.e. resources are provided to do something about the situation) or *personal* (i.e. skills are developed to deal with a situation), or a mixture of the two (Rootman & Raeburn, 1998). For example, if a person who lives in an oppressive macro-environmental situation (i.e. violent neighbourhood) feels there is some opportunity to exercise control over the situation (i.e. joining a community watch project) then the QOL impact of the oppressive situation could be moderated in a positive direction.

The Overall Quality of Life Field

Feedback loops are made from the quality of life *Outcome Circle* (which includes the three components of quality of life – B*eing, Belonging and Becoming*), to the QOL *Determinants Circle* (which includes *environmental* and *personal determinants*) and vice versa. This is included because changes in outcomes can result in changes in determinants, and changes in moderating conditions (Rootman & Raeburn, 1998). The entire arena of determinants, moderating conditions, and QOL outcomes, with feedback loops, is called the quality of life field. It is a complex domain of many parts and processes (Rootman & Raeburn, 1998).

Figure 3.3

Quality of Life Field



(Rootman & Raeburn, 1998, p.126).

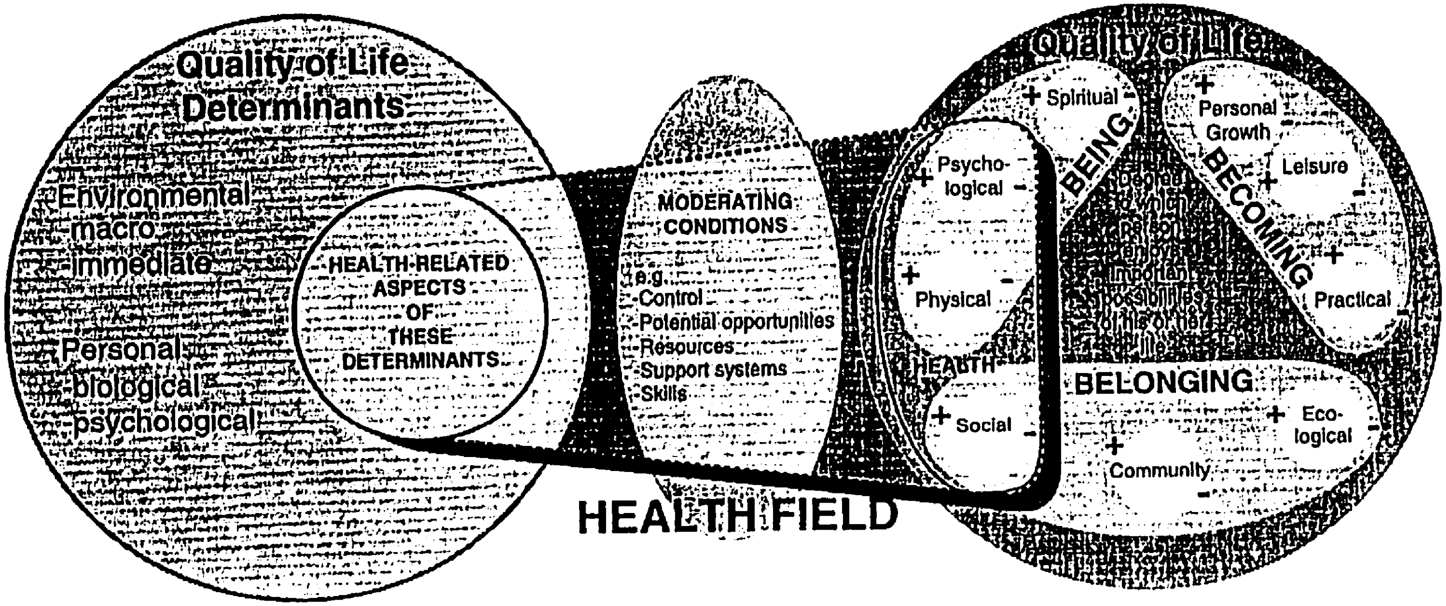
Health and Quality of Life

The quality of life framework continues to evolve, adding a new sub-field called *health*. Rootman and Raeburn (1998) explain that "it is important to distinguish the health-related aspects of the overall QOL components from the larger array, simply because in discussions of health (as distinct from QOL), different considerations obtain" (p.128). The creators of the framework dissect *health* from general quality of life to examine health-related issues. This dissection does not correspond to the present thesis, as general quality of life, rather than health-related quality of life, is the focus.

The researcher chooses to utilize the framework in its most holistic state. That is, the researcher will utilize the entire Quality of Life Field, without the inclusion of the Health Field (Health sub-field, health-related aspects of QOL determinants, and a limited ("ellipse") moderating conditions component) (Figure 3.4) for the purposes of this thesis. This is preferred in order to retain a comprehensive and holistic view of QOL, without focusing on one particular dimension of life quality. As the researcher maintains all components of QOL are interconnected and therefore impact each other, the framework must permit this.

Figure 3.4

Health-Related Quality of Life Field



(Rootman & Raeburn, 1998, p.129).

As mentioned previously, this framework provides a useful reference point from which to think about this study, and its results. This framework integrates very well with the quality of life perspective of the World Health Organization, as it is maintains a holistic perspective of quality of life. The framework and the World Health Organization consider several components of an individual's life as relevant aspects of quality of life. The framework also compliments the quality of life perspective of the World Health Organization through its recognition of the complexity of the quality of life concept, and the importance placed on the systems surrounding the individual and the context of the individual.

The quality of life framework presented in this chapter also corresponds with this thesis. The preceding chapters illustrated the holistic emphasis of this study. The review of care provider of PLWHA literature revealed a substantial number of issues that could enhance or diminish quality of life for a care provider. In addition, this chapter presented a variety of domains commonly used when assessing quality of life. The framework utilized for this study must be able to accommodate the encompassing structure developed in this thesis. This framework provides a broad conceptual reference point, and interconnects very well with the holistic nature of this thesis.

Summary

This chapter began with an introduction to quality of life as a concept, and exposed the diversity and disagreement inherent in quality of life. The origin of QOL studies was discussed. An examination of the difficulties defining quality of life was followed by the World Health Organization's definitions of health and quality of life.

The various QOL domains of study were then discussed. The debate between subjective and objective components of quality of life was also explained, and the importance of subjective criteria was established. Finally, the framework chosen for this thesis was described. Chapter Four describes the methodology whereby the quality of life of care providers of people with HIV or AIDS was explored empirically.

Chapter Four: Methodology

Introduction

Chapter One outlined the background of the thesis topic, the significance of the problem, and purpose of the study. Chapter Two provided an introduction to the existing caregiving literature in general terms, and explored various factors in the literature that can impact the quality of life of care providers of PLWHA. Chapter Three provided the conceptual foundation for this study. It introduced the concept of quality of life, described its origin, and discussed the challenges defining this concept. This was followed by an examination of the areas of consensus and disagreement within the QOL field of study. This chapter specifies the research question, and describes the research design and procedures. The setting, population and sample, sampling difficulties, instrumentation and other procedural parameters are also explained. Finally, methods of data analysis and methodological limitations are addressed.

Research Question

To this point, it is established that there are a variety of factors that may impact the quality of life of care providers of PLWHA, both negatively and positively. Yet, in the literature only one known study has examined this research area. Further examination of the quality of life of care providers of people living with HIV and AIDS requires the formulation of an appropriate research question. This exploratory question will "attempt to gather facts in a hitherto unmapped general problem area" (Grinnell, 1997, p.62).

In order to contribute to the understanding of how quality of life is impacted by providing care to a PLWHA, the following research questions are put forward:

- **What is the quality of life for care providers of people living with HIV/AIDS?**
- **Does the quality of life for care providers differ from the general population?**

Research Design and Procedures

This quantitative study examined the quality of life of two groups: care providers of people with HIV or AIDS, and a comparison group of social work students from the University of Calgary. This thesis is an exploratory study that seeks to investigate overall quality of life, and the impact of providing care on particular domains and facets of quality of life. An exploratory design was adopted because this question has never been addressed in the literature. Little is known about the quality of life of care providers of people with HIV or AIDS.

The design of this study is a comparison group, posttest only design. To investigate the quality of life of care providers, participants in this study completed a 100-question quality of life questionnaire. The participation of care providers for this study was facilitated through community AIDS organizations. An average quality of life score does not exist, and thus a comparison sample was utilized in order to compare care provider scores with scores from the general population. Students from the Faculty of Social Work at the University of Calgary were selected as the general population sample, on account of their accessibility, and the perception of students as a competent and seemingly well-adjusted group.

After receiving ethics approval from the University of Calgary, the largest community AIDS organization in Calgary, AIDS Calgary was approached in October 1998. After a meeting between the Executive Director, an agency employee, the researcher's thesis advisor and the researcher, arrangements were made with the Executive Director to disseminate consent letters (Appendix A) and questionnaires to care providers through particular agency staff members. Those employees of AIDS Calgary were instructed to approach care providers, that met the study criteria, with whom they had contact.

This indirect acquisition of respondents was implemented in order to maintain the confidentiality of client records. This approach also ensured that care providers did not feel obligated to complete the questionnaire by a third party with whom they were not familiar. After a number of months the cumulative number questionnaires were collected. Questionnaires from the general population respondents were disseminated and collected within the Faculty of Social Work classrooms. The following section discusses the setting, population and sample of the study.

Setting, Population and Sample

Central and Southern Alberta were the geographical areas selected for this study. HIV/AIDS organizations taking part in this study were located in Calgary, Edmonton, and Lethbridge, such as AIDS Calgary, HIV Edmonton and the Lethbridge HIV Connection. These organizations serve both urban and rural consumers. One support group of HIV positive individuals was also included. Participating organizations serve non-symptomatic people living with HIV, symptomatic people living with HIV, people with full-blown AIDS, and their support networks, including care providers, of PLWHA.

For the purposes of this study, a care provider is any adult who is self-defined as the primary, non-professional care provider for an adult with HIV or AIDS. Providers may be friends, partners, family members or volunteers. The term non-professional is used to distinguish those care providers who give care to a PLWHA without payment, from those professionals who are financially remunerated for caring (for example, nurses). The element of care is determined to be any kind of support or aid, whether instrumental (i.e. driving a PLWHA to a doctors appointment) or expressive (i.e. providing emotional support).

Care providers were initially defined as individuals with a previous relationship to the care recipient with HIV or AIDS (for example, friends, partners or family members). Utilizing care providers with a previous relationship to the PLWHA was beneficial in terms of caregiving information, as the majority of caregiving literature focuses on care providers with a previous relationship to the PLWHA. Difficulties obtaining respondents to complete questionnaires necessitated the expansion of sample criteria to include volunteer care providers as well. Because volunteers were not initially included in the design, respondents were not asked about their relationship to the care recipient. Therefore, the breakdown of caregivers with a previous relationship to the care recipient and those who volunteered as care providers is not known.

For the purposes of this study, the general population is defined any student from the Faculty of Social Work of the University of Calgary who does not provide care to a person with HIV or AIDS. On account of their accessibility, and the perception that this population would be a competent and rather well-adjusted group to study, respondents for the general population sample were collected from undergraduate and graduate level programs in the Faculty of Social Work of the University of Calgary.

An average score for the quality of life instrument utilized in this study does not exist, and therefore a comparison sample was necessarily used. In an ideal situation, a random sample of the general population would be accomplished, however for this study a random sample was not feasible. Students from the Faculty of Social Work were selected to circumvent financial and feasibility issues for the researcher. Utilizing a group of available individuals as a general population eliminated problems associated with large-scale sampling procedures, such as access to a large enough sampling frame and monies to carry out a substantial sampling process. A significant disadvantage to using a convenience sample however, is that it limits the opportunity to generalize the findings from this study (Grinnell, 1997).

The sampling strategy utilized for this design is based upon a convenience sample. Convenience sampling "relies on the closest and most available subjects to constitute the sample" (Grinnell, 1997, p.245). Employees of HIV/AIDS organizations identified and approached appropriate caregivers for the study through their professional relationships with care providers at the respective organizations. Employees disseminated and collected the quality of life questionnaires from care providers. Twenty-three care providers took part in the study.

Sixty-nine individuals comprised the general population sample. The researcher gathered the general population sample by approaching Faculty of Social Work professors. A written explanation of the study was given to professors, and the study was verbally explained. Professors acted as gatekeepers in terms of accessing classes of social work students at the University of Calgary. In the following section, the sampling difficulties encountered during the data collection phase of this study are documented.

Sampling Difficulties

Initially, the researcher intended to include care providers with a previous relationship to the care recipient (i.e. partner or friend), as the majority of caregiving literature concentrates on care providers with a previous relationship to the PLWHA. The anticipated response rate was not realized, despite continued communication between the researcher and the organization. After waiting for several weeks, the researcher approached the University of Calgary Ethics Committee to ask about expanding the existing study to other HIV/AIDS organizations in Calgary. This was approved. The response rate remained low.

After conferring with her advisor, the University of Calgary Ethics Committee, and the participating HIV/AIDS organizations in Calgary, the researcher widened the study's scope to include volunteer care providers as well. Another AIDS organization and a support group in Calgary were also approached in an attempt to increase sample size. The University of Calgary Ethics Committee was approached again, to request the expansion of the geographical area to Southern and Central Alberta. Two organizations in Edmonton and one organization in Lethbridge were contacted and agreed to participate.

From the period of October 1998 to June of 2000, a number of calls were made to organizations involved in the study. Despite attempts to encourage agency employees to disseminate the questionnaires to care providers, questionnaires were slow to return. Relying on agency employees to obtain quality of life questionnaires from care providers was clearly problematic. Respondents of the general population sample were gathered from the Faculty of Social Work at the University of Calgary. Disseminating questionnaires in one classroom did not yield a significant number of respondents. The sample was extended to include several social work classes to obtain a larger sample.

Operationalization

Quality of Life

Quality of life was operationalized by scores on the World Health Organization Quality of Life Assessment (WHOQOL) (Appendix B). In order to assess the quality of life of care providers of PLWHA and the general population, respondents were asked to subjectively rate (on a five-point Likert scale) their perceptions about personal QOL, based on six quality of life domains (physical, psychological, level of independence, social relationships, environment and spirituality). A series of 100 questions covering 24 specific facets (specific areas of life individuals consider to contribute to its quality) and one general quality of life facet were included.

Demographic Factors

Additional questions developed by the researcher to elicit relevant demographic information such as age, gender, marital status and level of education followed the questionnaire (Appendix C). Respondents were also asked about their individual serostatus. In addition, care providers were asked the date of diagnosis of the care recipient, and the present symptomatology of the care recipient. This series of demographic questions was posed to provide a description of the sample, and account for possible differences in quality of life scores. A detailed description of the WHOQOL Assessment is provided in the following section.

Instrumentation

Aims of the Instrument

Quality of life instrumentation addressing a broad range of concepts, populations and conditions is limited (Bonomi et al, 2000). The WHOQOL assessment was developed by the World Health Organization in response to the need for a genuinely international quality of life assessment and a commitment to the continued promotion of a holistic approach to health (Division of Mental Health, 1995b). The WHOQOL makes it possible to carry out quality of life research collaboratively in different cultural settings, and to compare directly results obtained in these settings (The WHOQOL Group, 1995). For example, care providers of people with HIV/AIDS in Canada can be compared to care providers in India or Zimbabwe.

The WHOQOL focuses on individuals' own views of their well being (Division of Mental Health, 1997). The World Health Organization Quality of Life Group (1996) states "a description of a person's quality of life should not reflect the opinions of health professionals or family members" (The WHOQOL Group, 1996, p.354). Indeed, the WHOQOL Group defends a self-evaluated, multidimensional and subjective approach to assessing life quality. The multidimensional and subjective components are apparent: "Assessment of the quality of life should be based on a broad range of criteria, not on a single issue such as pain. Where pain is experienced, the quality of life should be assessed by exploring what impact it has on the individual's independence and psychological, social and spiritual life, rather than by focusing exclusively on the pain itself" (The WHOQOL Group, 1996, p.354).

The WHOQOL defends the creation of a general quality of life instrument. As Bonomi et al. (2000) explain "without general quality of life measures, we are somewhat limited in our ability to measure general concerns of individuals who may not have a specific disease or condition of interest" (p.19). To date, no other quality of life instrument has been developed cross-culturally to address the comprehensive domains of the WHOQOL (Bonomi et al., 2000). The desire to construct a generic quality of life instrument for a variety of communities is fulfilled with the WHOQOL-100.

Development of the Instrument

The World Health Organization began work on the conceptualization and measurement of people's subjective quality of life in the mid-1980s (The WHOQOL Group, 1996). The WHOQOL-100 was developed simultaneously by WHO and fifteen collaborating field centres around the world (Division of Mental Health, 1997). Several culturally diverse centres were involved in operationalizing the instrument's domains of quality of life, drafting and selecting questions, generating response scales and pilot testing (The WHOQOL Group, 1995). Field centres were selected based on differences in industrialization, and other markers relevant to the measurement of quality of life (i.e. role of family, perception of self, dominant religion) (The WHOQOL Group, 1995).

Qualitative research was employed to examine the quality of life construct across cultures, to draft the preliminary questions, and to generate the response scales (The WHOQOL Group, 1995). The field centres used demographically representative focus groups of healthy individuals (including informal caregivers who provide care to "unwell"), individuals with disease/impairment (including acute/chronic, and outpatient/inpatient) and health personnel (including social workers, nurses, physicians) to generate ideas about quality of life (Division of Mental Health, 1993). Using same interview schedule with all groups, centres learned how people in different cultures wanted their quality of life to be assessed (The WHOQOL Group, 1996). In widely varying cultures, a remarkable amount of agreement about facets and questions thought appropriate was found (The WHOQOL Group, 1996).

On the basis of focus group data, questions were formulated into a "global question pool", and questions were reduced through content analysis, rank-ordering, and pilot testing health care users and healthy respondents (The WHOQOL Group, 1995). Simultaneous response scale development in different languages, following a standardized procedure, allowed researchers to avoid the perils of instrument translation, and produce a product initially available in 15 languages (Szabo, Orley & Saxena, 1997).

Continued psychometric testing reports the WHOQOL is valid and reliable instrument (The WHOQOL Group, 1998). The WHOQOL was initially administered to 300 individuals in each of the participating 15 culturally diverse field centres (The WHOQOL Group, 1998). Series of analyses revealed the instrument displays good discriminant validity, content validity and test-retest reliability (Division of Mental Health, 1997). The WHOQOL is currently available in more than thirty languages and in almost forty countries (WHO, 2000).

Structure of the Instrument

The structure of the instrument reflects issues that lay people and experts in the fifteen field centres felt were important to quality of life (Division of Mental Health, 1997). The instrument contains six broad domains of QOL, which are made up of individual quality of life facets. The six domains include physical health, psychological state, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. There are twenty-four quality of life facets, comprised of four items each, as well as four general items covering subjective overall QOL, which produces a total of 100 items in the assessment (Division of Mental Health, 1997). All items are rated on a five-point scale (1-5). The WHOQOL takes approximately 15 minutes to complete by self-report (Bonomi et al., 2000).

Each WHOQOL facet is characterized as a description of a behaviour, a state of being, a capacity or potential, or a subjective perception or experience (Division of Mental Health, 1995a). To illustrate this characterization, consider for example, pain is a subjective perception or experience, fatigue may be defined as a state of being, mobility may be defined as a capacity (ability to move around) or as a behaviour (actual report of walking) (Division of Mental Health, 1995a). According to the differences in content of WHOQOL questions, four response scales were developed. These scales include *intensity* (i.e. the degree of pain experienced); *capacity* (i.e. the capacity to carry out daily activities); *frequency* (i.e. the frequency of despair); and *evaluation* (i.e. the appraisal of personal relationships) (Szabo et al., 1997).

The WHOQOL produces scores relating to particular facets of quality of life (for example, positive feelings or financial resources), scores relating to larger domains (for example, physical or social relationships), and a score relating to overall quality of life (Division of Mental Health, 1997). Organizing items into facets and domains allows researchers to compare individual facet and domain scores of respondents or groups of respondents, as well as comparing overall quality of life scores. Thus, researchers can identify individual perceptions of QOL, and determine their quality of life relative to other populations. In addition, by comparing different domains within a total score, researchers can determine particular domains of quality of life that are higher or lower than others.

Advantages of Using the WHOQOL

Several features of the WHOQOL give this instrument advantages over other quality of life assessments. The WHOQOL can be applied across a wide range of cultural and socio-economic settings (Bartos, 1998). This assessment is now available in more than thirty languages, and bypassed the post-development translation process, which can be a barrier to comparing results from various cultures. The WHOQOL lends itself to international comparison, as quality of life can be compared across countries and cultural subgroups within countries (Bonomi et al., 2000).

The WHOQOL is a generic instrument. It can be utilized with a variety of populations, and in many situations. According to Bonomi et al. (2000), "the features of the WHOQOL make it an appropriate tool for assessing the effects of interventions both health and non-health related…" (p. 11). This assessment allows researchers to assess how well and unwell individuals evaluate their quality of life. This instrument can be used with care providers, because it was developed with input from care providers and "well" individuals.

The multifaceted nature of the WHOQOL is another advantage of this assessment. The WHOQOL provides a balanced and holistic assessment of a person's quality of life. This assessment identifies six domains of a person's life thought to be significant by people in 15 countries, globally. The coverage of quality of life that results provides a conceptual coherence, or gestalt, which is missing from many other measures of quality of life. (Szabo, on behalf of the WHOQOL Group, 1996).

This assessment is also exceptional in the arena of quality of life measures, because of the inclusion of positive aspects of quality of life. In an examination of the most frequently used quality of life measures, Carr et al. (1996) found:

> …with the exception of the new WHO instrument, all quality of life measures assess only the negative aspects of health, whereas any personal assessment of quality of life consists of a weighing-up of the balance of the negative and positive aspects. In other words, these tools are not measuring quality of life *per se*, but whether the patient's health has a negative impact on his quality of life (p.278).

It can be inferred from this statement that because the WHO instrument considers aspects other than health as important, this tool will measure the positive and negative aspects of other domains of a person's life as well.

The World Health Organization Quality of Life assessment can be utilized in a variety of practical ways. The WHOQOL can be used in clinical practice, "giving valuable information that can indicate areas in which a person is most affected" and can help the practitioner in making the best choices for care and treatment (Division of Mental Health, 1997, p.2). Bonomi et al. (2000) describe two additional specific practical uses for the WHOQOL: to evaluate the effects of program interventions on the QOL of individuals, and to measure change over time related to specific life circumstances of individuals. Finally, the WHOQOL is advantageous for research and policy making. Utilizing the WHOQOL on different populations of individuals can provide insight into how a significant event in one domain of a person's life can impact the subjective well being of a person across a whole range of areas (Division of Mental Health, 1997).

Such assessments can also encourage social and health care professionals to focus attention on the positive aspects of people's lives and how they can be strengthened (The WHOQOL Group, 1996). Indeed, a consideration of the subjective quality of life is likely to lead to an improvement in the services provided to consumers in many spheres of the community, which prefaces an improvement in the quality of lives of consumers. The following section describes the data analysis techniques that were used to analyze the WHOQOL assessment scores.

Data Analysis Techniques

As this was primarily an exploratory study, frequency and descriptive analyses were used to reflect the data. Descriptive analyses were used to describe the sample and information about the diagnosis and serostatus of care recipients. Descriptive statistics were also utilized to describe particular quality of life facet questions. A series of t-tests were employed to analyze individual facet questions for significant differences between the scores of care providers and the general population.

To test for significant differences between care providers and the general population in terms of overall quality of life and individual domain scores, additional t-tests were utilized. Descriptive statistics were employed to describe individual quality of life domain scores. SPSS (Statistical Program for the Social Sciences) software was utilized in executing the statistical analyses. The final section of this chapter examines the limitations of this research study.

Limitations of Research

There are several limitations to this study to consider. In terms of internal validity, the effects of history, maturation, testing, and mortality (Grinnell, 1997) are minimal in this research design given that only one measurement was initiated. Three threats to internal validity do apply: reactive effects and differential selection of research participants, and instrumentation error. Research participants in this study may change their behaviour or feelings as a reaction to the novelty of the situation or the knowledge that they are participating in a research study (Grinnell, 1997). In addition, random assignment to groups was not possible for either the care providers or the general population, which is a threat to the internal validity of the study (Grinnell, 1997). Finally, administering the questionnaires in AIDS community organizations and classrooms may impact the responses of participants, which is an example of instrumentation error.

A convenience sample was obtained, rather than a random sample, which effects the external validity of the study. It is not possible to determine to what degree caregivers in this sample are representative of all caregivers in other geographical locations (Grinnell, 1997). This is largely due to the fact that HIV-positive people who meet the criteria for the study resulted in a non-randomized sample. Lacking access to caregivers through agency files, and working with a limited budget, a convenience sample was the feasible option.

The generalizability of findings is limited by a variety of factors. The sample size is very small, and only caregivers of one conservative province were studied, which is an external threat to validity, particularly the specificity of variables (Grinnell, 1997). Specificity of variables, according to Grinnell (1997) implies that "a research project conducted with a specific group of people at a specific time and in a specific setting may not always be generalizable to other people at a different time and in a different setting" (p.277). Studies about the quality of life of care providers of PLWHA in larger urban centres or remote regions, or different political climates, may yield different results.

The defining parameters for the care provider sample were very diverse, allowing for the inclusion of family members, partners, volunteers, or friends. The encompassing definition of care provision utilized in this study includes variation in commitment of informal caregivers and the situational contexts of their caregiving. These factors could potentially generate different results in further research. Such broad parameters limit the generalizability of the findings as well.

Summary

Chapter Four described this study's research design, data sources, instrumentation, and analyses. The research question was presented and operationalized. An explanation of the instrumentation utilized for this study was given. The demographic characteristics of the samples were described, and the procedures followed to obtain the samples were documented. Statistical procedures used and methodological limitations were also reviewed in this chapter. The following chapter presents the results from addressing the research questions of this study.

Chapter Five: Results

Introduction

Data collected through questionnaire completion are presented in this chapter. Descriptive data pertaining to the sample will first be presented followed by descriptive data about the year of diagnosis and the symptomatology of care recipients. Descriptive data about particular quality of life facet questions are then presented. Individual facet questions are analyzed for significant differences between care providers and students (general population), and results of these analyses of variance are presented within individual facet question data. This is followed by further analyses with overall quality of life and specific quality of life domains to test for significant differences between scores of care providers and students. This chapter is concluded with the presentation of measures of central tendency and variability for individual domain scores.

Sample Characteristics

In order to describe the characteristics of care providers and students, a series of questions were posed to respondents to solicit specific personal information. Respondents were asked about their age, gender, level of education, and marital status. In addition, care providers were asked to identify the care recipient's year of diagnosis with HIV, and whether they were HIV-positive without symptomatology, HIV-positive with symptomatology, or with full-blown AIDS. Finally, respondents were asked to provide their own HIV serostatus.

Information about the gender, age, education and marital status of respondents is provided in Table 5.1. Care providers in this sample were equally represented by male (n=11) and female (n=12) caregivers. Student respondents were predominantly female (n=58), with only 14.7% of students reported being male (n=10). Care providers ranged in age from 20-79. The two age groups 30-39 years, and 40-49 years were represented equally among care providers with seven individuals (30.4%) each. These groups represented the most prevalent age groups in the sample. Student respondents were younger as a group: their ages ranged from 20-59. Students were predominately 20-29 years of age (56.7%) or 30-39 years of age (25.4%).

Care providers and student respondents represent a well-educated group as a whole. Seventeen care providers (77.3%) in this sample indicated they received education at the college, university or post-graduate level, while 100% of student respondents specified they were educated at one of these levels.

An examination of marital status revealed a number of scenarios. Ten caregivers indicated they were single (45.5%), 4 indicated they were married (18.2%), 3 indicated they were living as married (13.6%) and 3 indicated they were divorced (13.6%) as a sample. Thirty-five (51.5%) respondents from the student sample indicated they were single, followed by 21 (30.9%) who were married, and 8 (11.8%) who were living as married.

Table 5.1
Distributions of Respondents for Gender, Age, Education and Marital Status

	Care Provider		Student	
Variable	n	%	n	%
Gender:				
Males	11	47.8	10	14.7
Females	12	52.2	58	85.3
Total	23	100.0	68	100.0
Age Group:				
20-29	1	4.3	38	56.7
30-39	7	30.4	17	25.4
40-49	7	30.4	7	10.4
50-59	2	8.7	5	7.5
60-69	4	17.4	0	0.0
70-79	2	8.7	0	0.0
Total	23	100.0	67	100.0
Education Level:				
Primary School	1	4.5	0	0.0
Secondary School	4	17.4	1	1.5
University/College	11	50.0	57	83.8
Postgraduate	6	27.3	10	14.7
Total	23	100.0	68	100.0
Marital Status:				
Single	10	45.5	35	51.5
Married	4	18.2	21	30.9
Living as Married	3	13.6	8	11.8
Separated	0	0.0	2	2.9
Divorced	3	13.6	2	2.9
Widowed	2	9.1	0	0.0
Total	22	100.0	68	100.0

Caregivers were asked to provide information about the care recipient as well (Table 5.2). Care providers were asked when their care recipient was first diagnosed with a positive HIV test. Five care recipients were primarily diagnosed between 1986 and 1990 (41.7%), followed by 4 recipients in 1991-1995 (33.3%), and 3 recipients in 1996-2000 (25.0%). An examination of the present HIV/AIDS stage of disease of the recipient revealed a split between 7 care recipients who were HIV-positive with symptomatology (46.7%), and 6 recipients with full-blown AIDS (40.0%). Two care recipients (13.3%) were HIV-positive without symptomatology.

Table 5.2
Distributions of Care Recipient Diagnosis Years
And Present HIV/AIDS Stage of Disease

Variable	n	%
Year of Positive Test:		
1986-1990	5	41.7
1991-1995	4	33.3
1996-2000	3	25.0
Total	12	100.0
Stage of Disease:		
HIV-positive without Symptomatology	2	13.3
HIV-positive with Symptomatology	7	46.7
Full-Blown AIDS	6	40.0
Total	15	100.0

Respondents were also asked about their own HIV status (Table 5.3). In this sample of 23 care providers no positive tests were reported. Two individuals (7.7%)

from the student sample, however, indicated they were HIV-positive. Sixty-two percent of the student respondents did not answer this question.

Table 5.3
Percentage of Positive HIV Tests for Respondents

	Care Provider		Student	
	n	%	n	%
Positive Test	0	0.0	2	7.7
Negative Test	23	100.0	24	92.3
Total	23	100.0	26	100.0

The following section reaffirms the research questions of this study, and explains the component parts and the scoring of the WHOQOL questionnaire.

Quality of Life of Care Providers of PLWHA

The purpose of this study is to answer the following questions: What is the quality of life for care providers of people living with HIV/AIDS? Does the quality of life for care providers differ from the general population? In order to determine whether the quality of life of care providers of people living with HIV or AIDS is lower, a series of questions were posed to caregivers and the student population to solicit quality of life information.

Respondents in this study completed the 100-question World Health Organization Quality of Life questionnaire. Care providers and student respondents were asked to assess their general quality of life, as well as answer questions regarding several domains of quality of life, including physical, psychological, level of independence, social relationships, environment, and spirituality. These domains were further compartmentalized into quality of life facets. The questionnaire was composed of four general quality of life questions, and 24 facets (which form the six QOL domains), each consisting of four questions. A list of these facets is available in (Appendix D).

Each of the facet questions corresponds to a facet (or sub-domain) which in turn corresponds to one of the six individual quality of life domains. For example, the question "How often do you suffer (physical) pain?", is a facet question. This is one question from a total of four, from the "Pain and Discomfort" facet. The "Pain and Discomfort" facet is one of three facets composing the physical domain of quality of life. Examples of facet questions from each of the other quality of life domain illustrate the composition of the questionnaire.

The psychological domain includes questions about feelings, self-esteem and learning, such as is "How much do you value yourself?". An example of a facet question from the level of independence domain, is "How well are you able to get around?". "How satisfied are you with your personal relationships?" is a facet question from the social relationships domain, which includes questions about relationships, support and sexual activity. Questions assessing the environment domain include "How comfortable is the place where you live?". Finally, an example of a facet question from the spirituality/religion/personal beliefs domain is "Do your personal beliefs give meaning to your life?".

The WHOQOL produces a quality of life profile that calculates individual domain scores and an overall quality of life score. All scores are scaled in a positive direction (higher scores denote higher quality of life). WHOQOL instruction manuals indicate the examination of the individual domain scores is preferred to an examination of the total QOL score (Division of Mental Health, 1995c). A brief overview of the total quality of life score and an explanation of the individual QOL domain scores from this study are presented following a description of the results from individual facet questions. The following section presents the results of participants' responses to individual facet questions that yielded interesting differences.

Individual Facet Questions

Individual quality of life facet questions provided interesting variability in responses. The frequencies of this study revealed many similarities between care providers and students. However, particular facet questions yielded differences in responses that reveal where care providers or students scored particularly high or low. These facet questions are described below.

Independent t-tests were employed to investigate differences in facet question scores. The t-test was used to test the significance of the differences between the mean scores of care providers and students for individual facet questions. Statistically significant differences were found for six individual facet questions, and these results are included in the following facet question discussion.

The selected individual facet questions appear under their respective domains as a method of illustrating how these questions fit into the broader domain scores. This is also accomplished to highlight how care providers and students critically evaluate facets across a range of domains, rather than assessing one domain in particular as significantly lower. The first section presents data from the general quality of life questions included in the WHOQOL.

Overall Quality of Life and Health (General Questions)

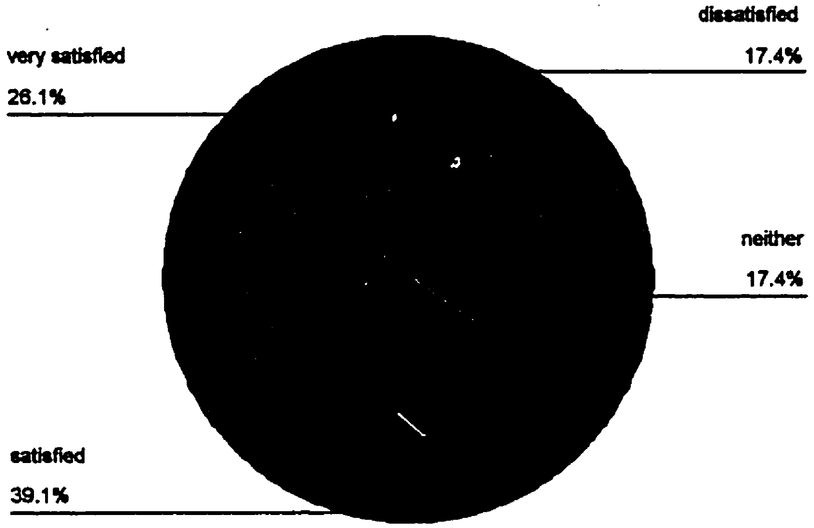
Quality of Life

Overall Quality of Life and Health questions "examine the ways in which a person assesses his/her overall quality of life, health and well-being" (Division of Mental Health, 1995a). When asked "How satisfied are you with the quality of your life?", care providers supplied a variety of responses (Figure 5.1). Thirty-nine percent (n=9) were "satisfied" with the quality of their life, and 26.1% (n=6) were "very satisfied". It is apparent however, that several caregivers are not satisfied with their QOL: four care providers were "dissatisfied" (17.4%), and four individuals were "neither satisfied nor dissatisfied" (17.4%) with their quality of life.

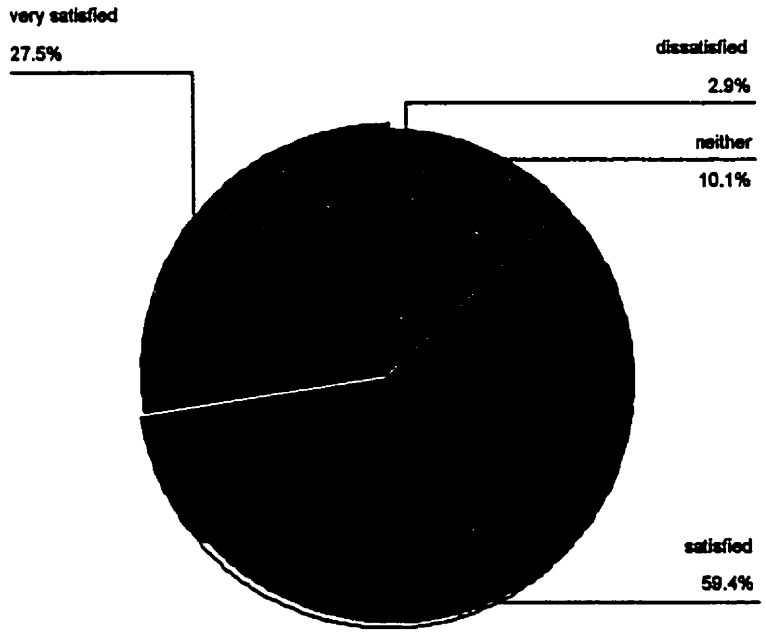
The student population evaluated their satisfaction with the quality of their life more positively: 59.4% were "satisfied", and 27.5% were "very satisfied". Two individuals (2.9%) were "dissatisfied" and 7 individuals from the student population (10.1%) were "neither satisfied nor dissatisfied". Clearly the majority of students are satisfied with their quality of life.

Figure 5.1
How satisfied are you with the quality of your life?

Care Provider



Student

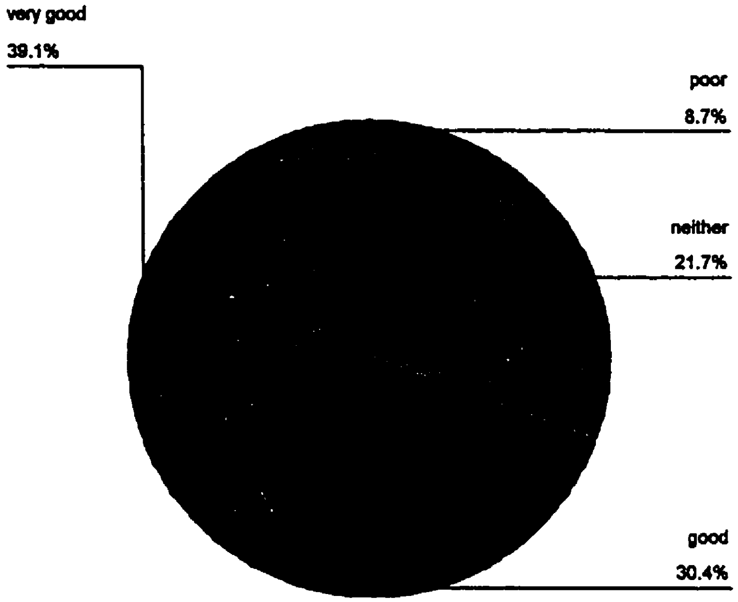


Care providers also rated their quality of life as poorer than the student population when asked "How would you rate your quality of life?". There was a statistically significant difference in the scores of care providers and students for this question. A t-test showed that the mean score for care providers was 3.91, whereas the mean score for students was 4.28 ($t=-2.293$, $p<.024$). Figure 5.2 illustrates that almost 70% of caregivers ($n=16$) rated their quality of life as "good" (30.4%) or "very good" (39.1%). Yet, additional results demonstrate that several care providers did not evaluate their quality of life favourably. Five care providers (21.7%) rated their quality of life as "neither poor nor good", and 2 care providers (8.7%) rated their quality of life as "poor".

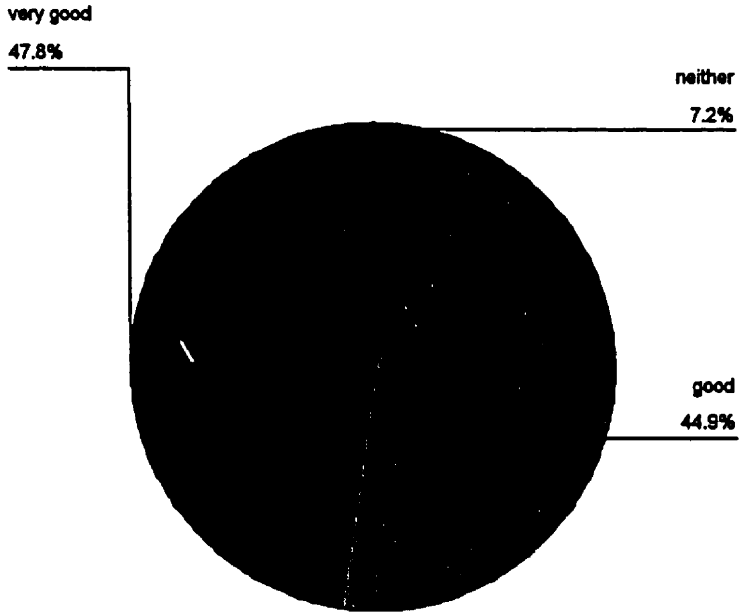
In contrast, the vast majority of students rated their quality of life positively. Over ninety percent of students rated their quality of life as "good" (44.9%) or "very good" (47.8%). Five respondents (7.2%) rated their quality of life as "neither poor nor good". There were no "poor" ratings from student respondents.

Figure 5.2
How would you rate your quality of life?

Care Provider



Student

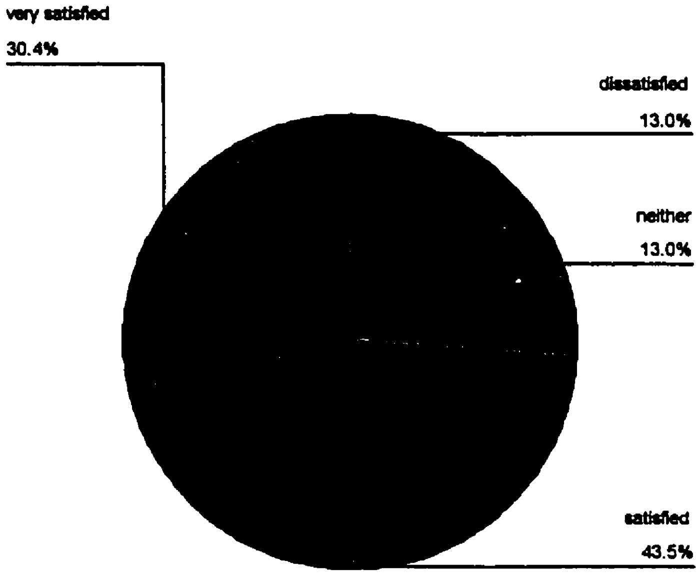


Care providers were less satisfied with their lives in general. When questioned "In general, how satisfied are you with your life?" (Figure 5.3), the majority of care providers were "satisfied" (43.5%), and "very satisfied" (30.4%). However, it is again apparent that several care providers are not satisfied with their lives. Thirteen percent (n=3) of care providers were "neither satisfied nor dissatisfied", and 13% were dissatisfied with their life in general.

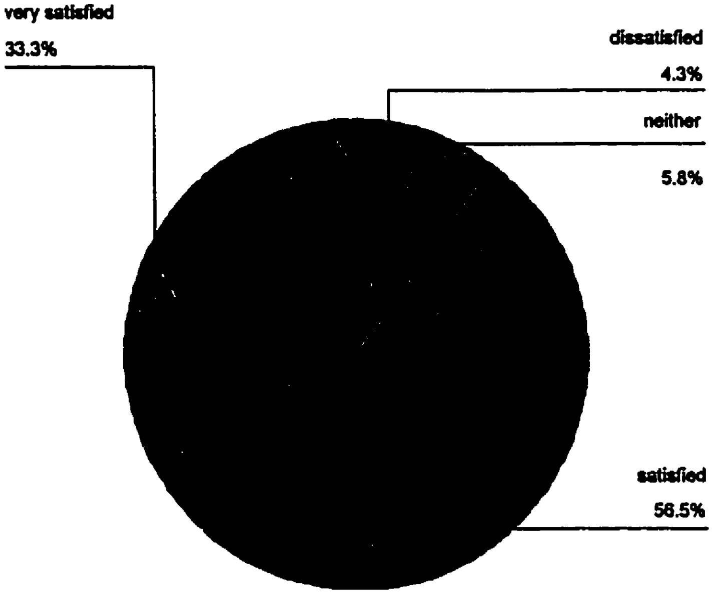
Students revealed similar trends to their previous responses as well: the student population indicated they were primarily "satisfied" (56.5%) and "very satisfied" (33.3%) with their lives in general. A small percentage (5.8%) of students were "neither satisfied nor dissatisfied" with their lives in general, and 4.3% were "dissatisfied in the student sample.

Figure 5.3
In general, how satisfied are you with your life?

Care Provider



Student



Physical Domain

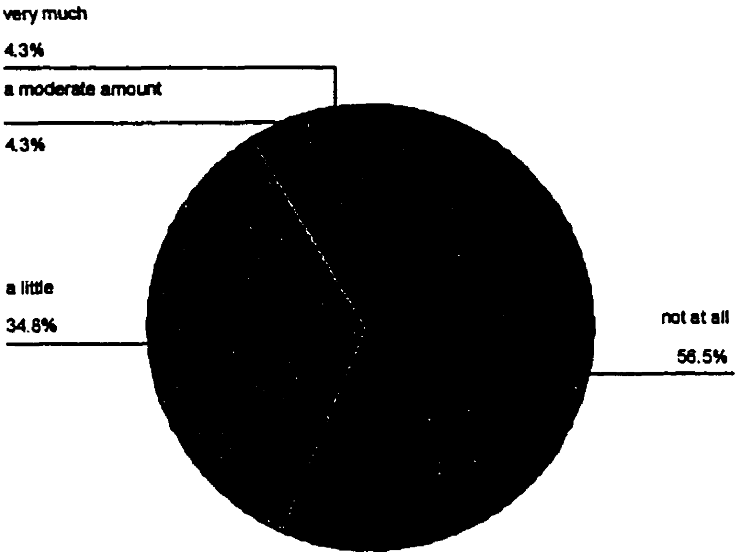
Pain and Discomfort Facet

The first facet of the physical domain is known as the Pain and Discomfort facet which "explores unpleasant physical sensations experienced by a person and the extent to which these sensations are distressing and interfere with life" (Division of Mental Health, 1995a). Respondents were asked "To what extent do you feel that (physical) pain prevents you from doing what you need to do?" (Figure 5.4). The majority of care providers (n=13) reported that physical pain does not prevent them from doing what they need to do (56.5%). Eight caregivers noted pain only prevents them "a little" (34.8%). Only one care provider (4.3%) indicated that physical pain prevents them "very much" from doing what they need to do.

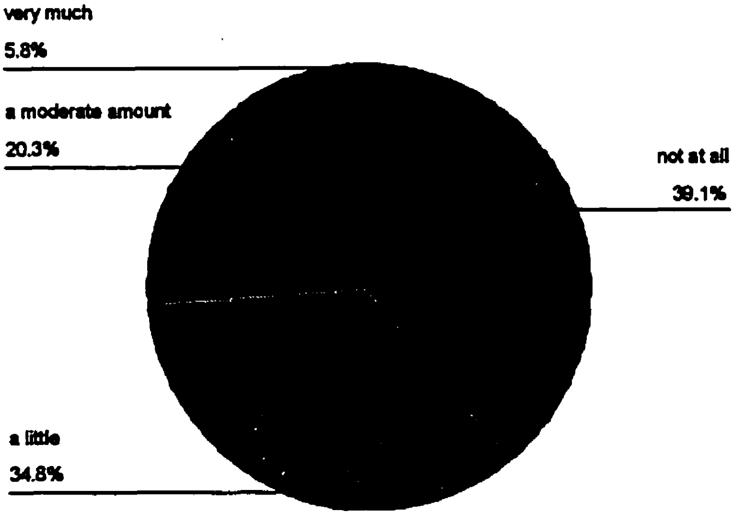
Students reported that physical pain prevented them "not at all" (39.1%) or "a little" (34.8%) from doing what they need to do. However, pain clearly interfered with the productivity of the student population. Student respondents indicated that physical pain prevents them "very much" (5.8%) or "a moderate amount" (20.3%) from doing what they need to do.

Figure 5.4
To what extent do you feel that (physical) pain prevents you from doing what you need to do?

Care Provider



Student

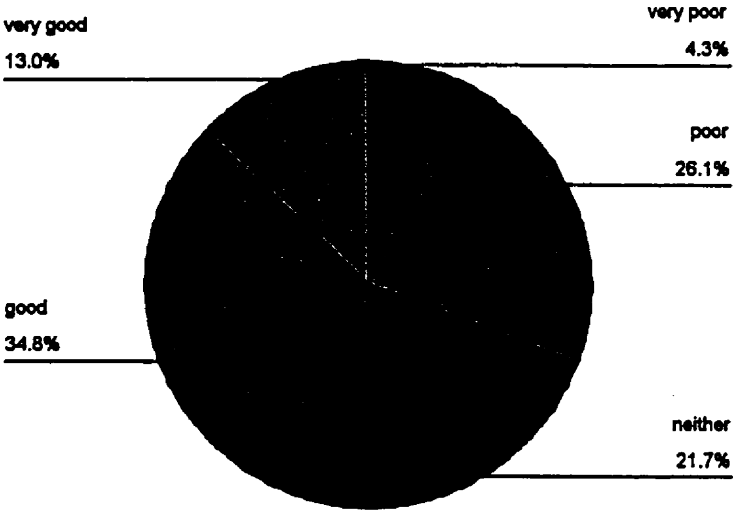


Sleep and Rest Facet

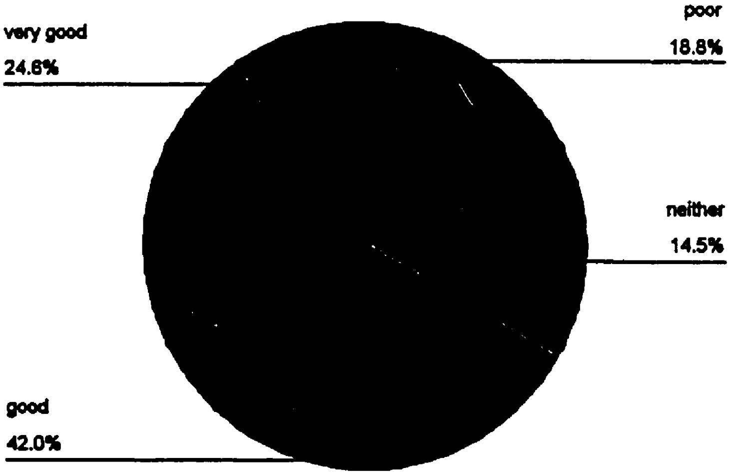
The Sleep and Rest facet "concerns how much sleep and rest, and problems in this area, affect the person's quality of life" (Division of Mental Health, 1995a). Care providers and students evaluated their sleep poorly. Care providers, in particular, cite deficits in sleep. When asked "How well do you sleep?" (Figure 5.5), one care provider cited "very poor" (4.3%), while 26% cited "poor". Eight caregivers indicated they sleep well (34.8%) and three care providers evaluated their sleep as "very good" (13%). Less than twenty percent (18.8%) of student respondents indicated their sleep is "poor". The majority of students are positive about how well they sleep. Sixty-six percent of students reported "good" (42%) or "very good" (24.6%) sleep.

Figure 5.5
How well do you sleep?

Care Provider



Student

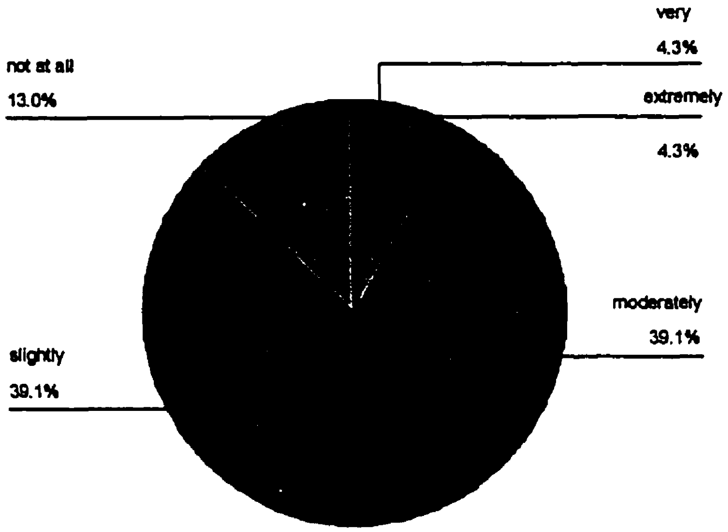


Energy and Fatigue Facet

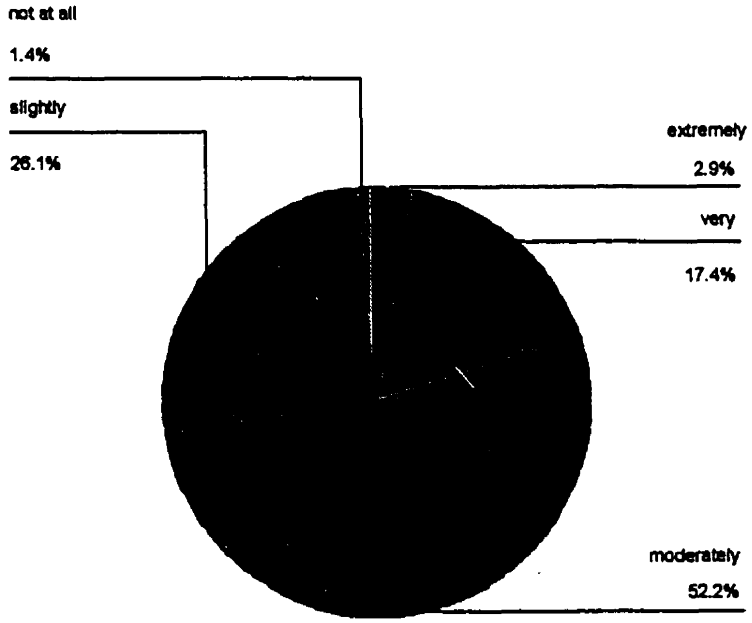
The Energy and Fatigue facet "explores the energy, enthusiasm and endurance a person has to perform the necessary tasks of daily living, as well as other chosen activities such as recreation" (Division of Mental Health, 1995a, p.4). A statistically significant difference was found between scores for the question "How easily do you get tired?". Care providers' mean score was 3.53, while students scored 3.06 (t=2.330, p<.022). Frequencies revealed that students are more easily tired (Figure 5.6). Nine care providers reported getting "slightly" (39.1%) or "moderately" (39.1%) tired. Only two care providers reported they easily are "very" (4.3%) or "extremely" (4.3%) tired. While almost 80% of the student population indicated they are easily "slightly" (26.1%) or "moderately" (52.2%) tired, 12 individuals reported they easily get "very" (17.4%) tired. In addition, two students (2.9%) reported they easily get "extremely" tired.

Figure 5.6
How easily do you get tired?

Care Provider



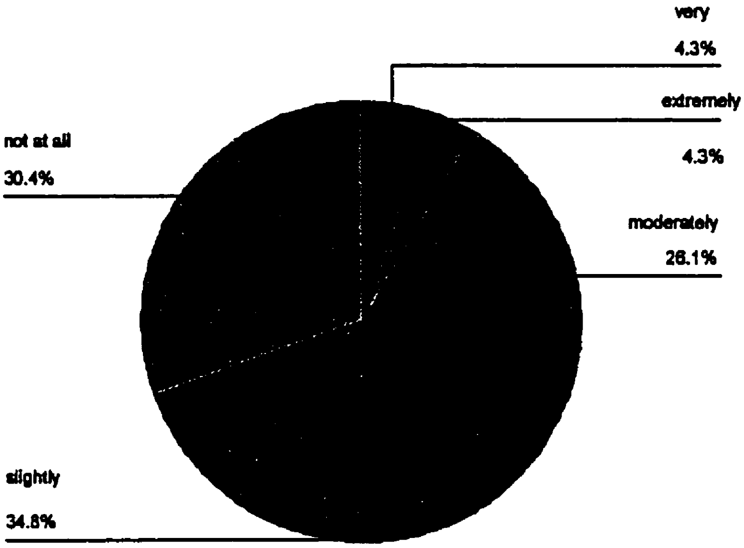
Student



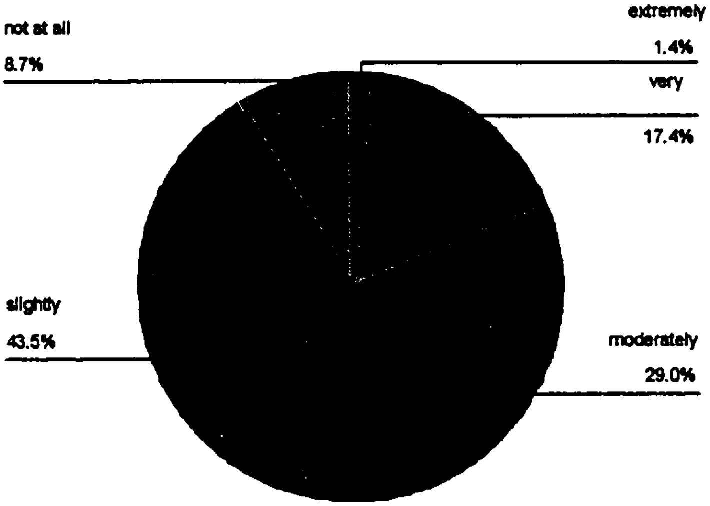
Another Energy and Fatigue facet question within the physical domain is "How much are you bothered by fatigue?" (Figure 5.7). Students in this sample indicated they are more bothered than care providers. While six care providers (26.1%) were "moderately" bothered by fatigue, only two caregivers were "very" (4.3%) or "extremely" (4.3%) bothered. Twenty-nine percent of student respondents were "moderately" bothered by fatigue. The largest differences were apparent at the extreme end of the scale. Twelve students (17.4%) indicated they were very bothered, and one student was "extremely" (1.4%) bothered by fatigue.

Figure 5.7
How much are you bothered by fatigue?

Care Provider



Student



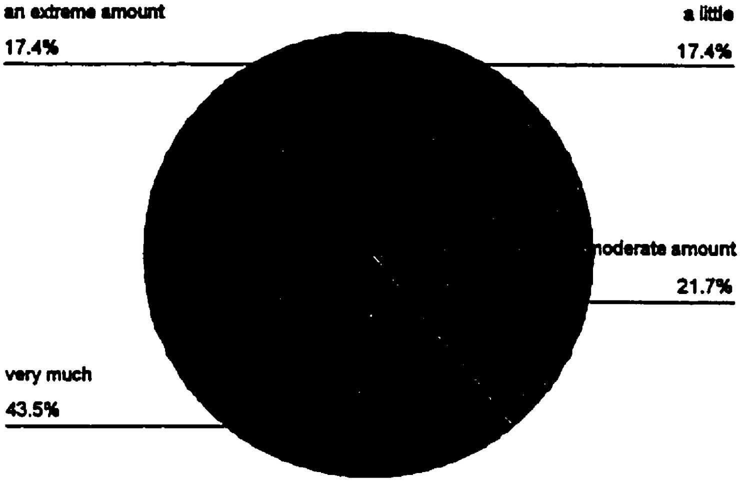
Psychological Domain

Self-esteem Facet

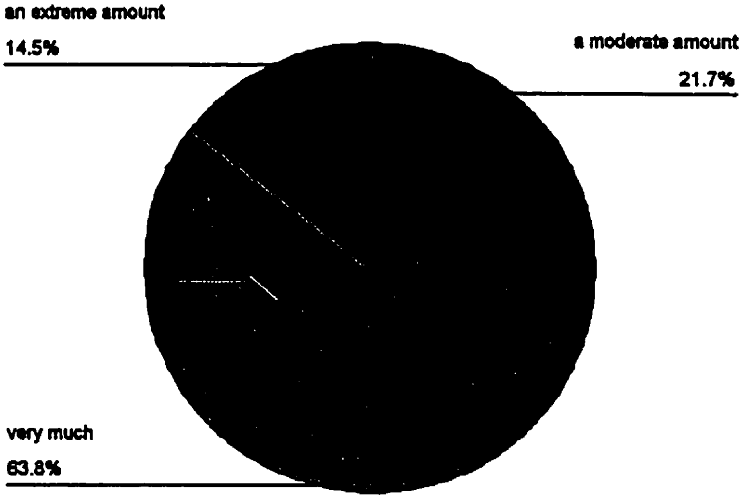
The Self-esteem facet of the psychological domain "examines how people feel about themselves" (Division of Mental Health, 1995a). Care providers and student respondents were asked "How much confidence do you have in yourself?" (Figure 5.8). Students report higher levels of self-confidence overall. The majority of care providers were very (43.5%) or extremely (17.4%) confident. Five care providers (21.7%) had "a moderate amount" of confidence in themselves, and four caregivers (17.4%) had only "a little" confidence. The students in this sample reported high levels of self-confidence. Ten students had extreme confidence in themselves (14.5%), while 86% of students reported very to moderately confident. There were no reports of "a little" confidence among the students.

Figure 5.8
How much confidence do you have in yourself?

Care Provider



Student



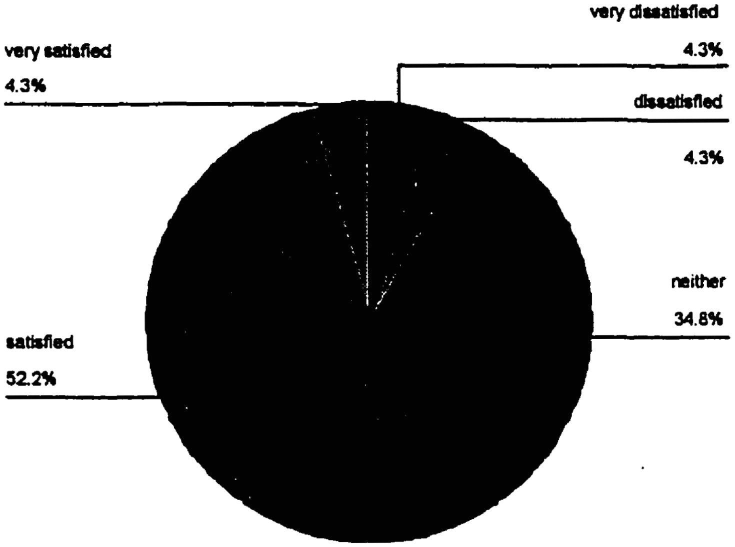
Body Image and Appearance Facet

The Body Image and Appearance facet "examines the person's view of his/her body" ("Division of Mental Health," 1995). Respondents were asked to evaluate "How satisfied are you with the way your body looks?" (Figure 5.9). The majority of care providers were satisfied with their bodies. Only two care providers indicated they were "very dissatisfied" (4.3%) or "dissatisfied" (4.3%). More than half of caregivers (52.2%) were "satisfied" with the way their bodies look.

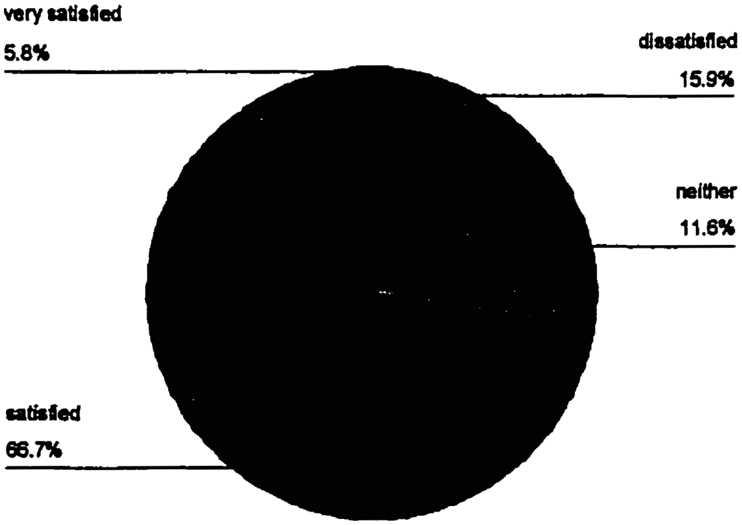
Several students revealed dissatisfaction with their bodies. No respondents in the student population were "very dissatisfied", but 15.9% were "dissatisfied" with the way their bodies look. Almost seventy percent were "neither satisfied nor dissatisfied" (11.6%) or "satisfied" (66.7%) with the way their bodies look.

Figure 5.9
How satisfied are you with the way your body looks?

Care Provider



Student



Social Relationships Domain

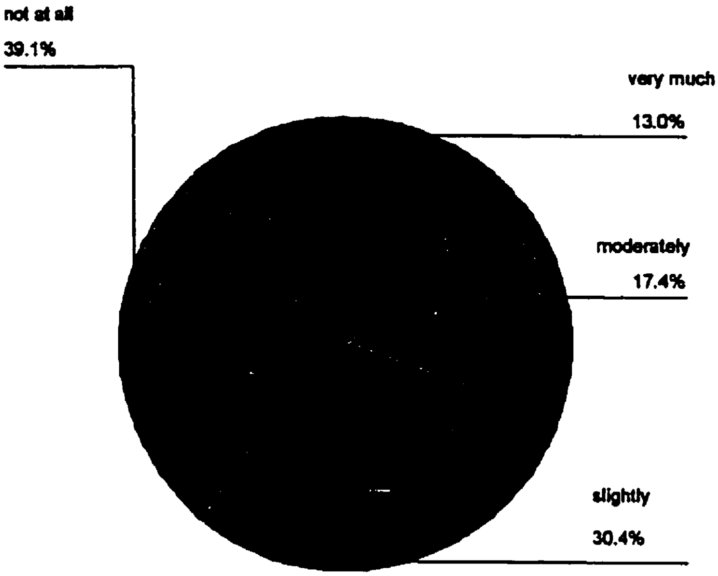
Personal Relationships Facet

The Personal Relationships facet of the social relationships domain "examines the extent to which people feel the companionship, love and support they desire from the intimate relationship(s) in their life. This facet also addresses commitment to and current experience of caring for and providing for other people" ("Division of Mental Health," 1995). When asked "How alone do you feel in your life?", it was apparent that more care providers than students felt alone (Figure 5.10). The majority of care providers indicated they didn't feel alone (39.1%), or felt only "slightly" (30.4%), or "moderately" (17.4%) alone. However, three care providers in the sample (13%) felt "very much" alone in their lives.

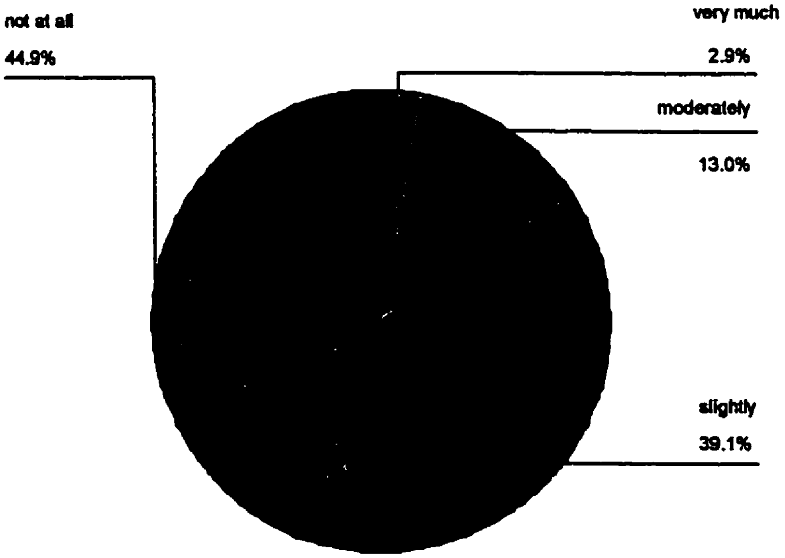
Students maintained higher self-assessments of feeling alone. Within the student population, almost half the sample (44.9%) did not feel alone. A number of students felt "slightly" (39.1%) or "moderately" (13%) alone. Only 2.9% of the student respondents felt "very much" alone in their lives.

Figure 5.10
How alone do you feel in your life?

Care Provider



Student

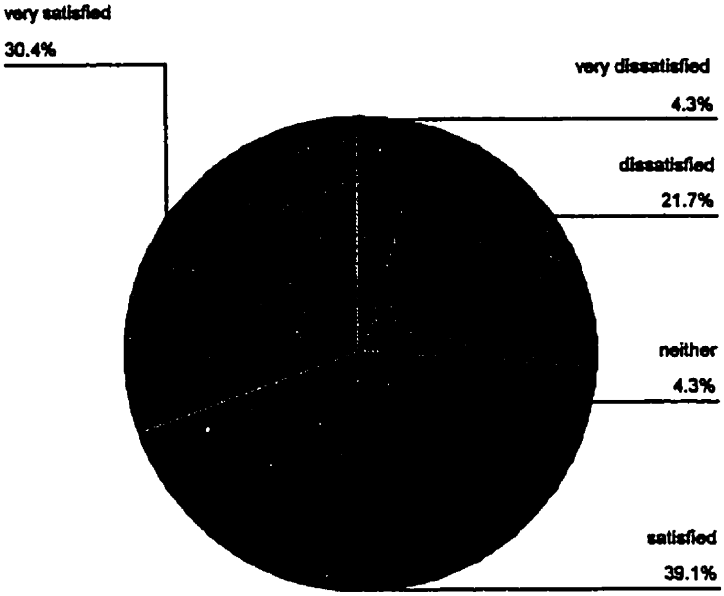


Respondents were asked “How satisfied are you with your personal relationships?” from the Personal Relationships facet of the psychological domain (Figure 5.11). Results indicated that care providers are less satisfied with their personal relationships than students. The majority of caregivers were “satisfied” (39.1%) or “very satisfied” (30.4%) with their personal relationships. However, several care providers expressed dissatisfaction with relationships. One individual (4.3%) was “very dissatisfied” and five individuals (21.7%) were “dissatisfied” with their personal relationships.

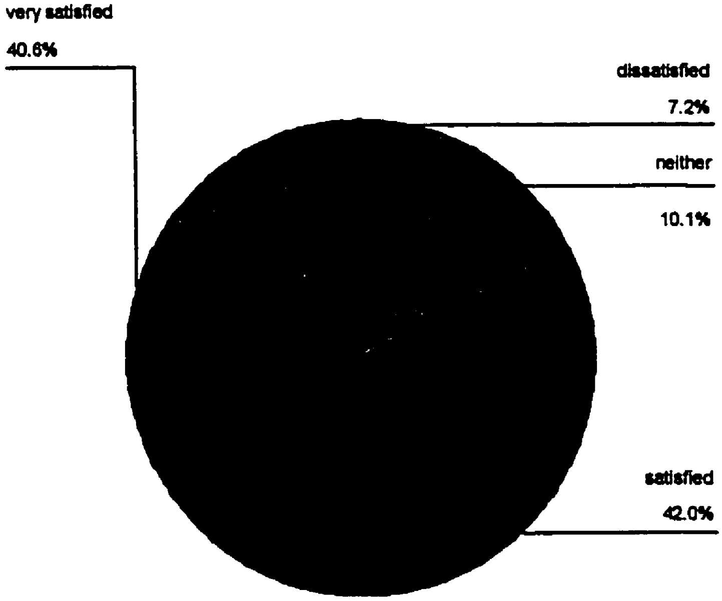
The student population assessed their satisfaction more positively. Forty-two percent of students evaluated their personal relationships as satisfactory, and 40.6% were “very satisfied”. Only 7.2% indicated they were “dissatisfied”.

Figure 5.11
How satisfied are you with your personal relationships?

Care Provider



Student



Environment Domain

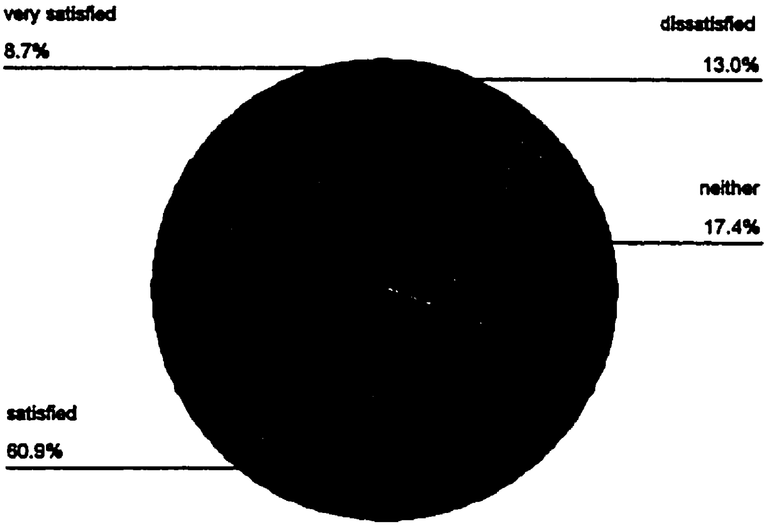
Opportunities for Acquiring Information and Skills Facet

The Opportunities for Acquiring Information and Skills facet of the environment domain "examines a person's opportunity and desire to learn new skills, acquire new knowledge, and feel in touch with what is going on" ("Division of Mental Health," 1995). Respondents were asked to evaluate "How satisfied are you with your opportunities for acquiring new skills?" (Figure 5.12). It is apparent from these results that care providers perceive a need for more opportunities to acquire new skills. A t-test demonstrated that care providers (M=3.65) were significantly less satisfied with their opportunities for acquiring new skills than students (M=4.22) (t=-3.879, p<.000).

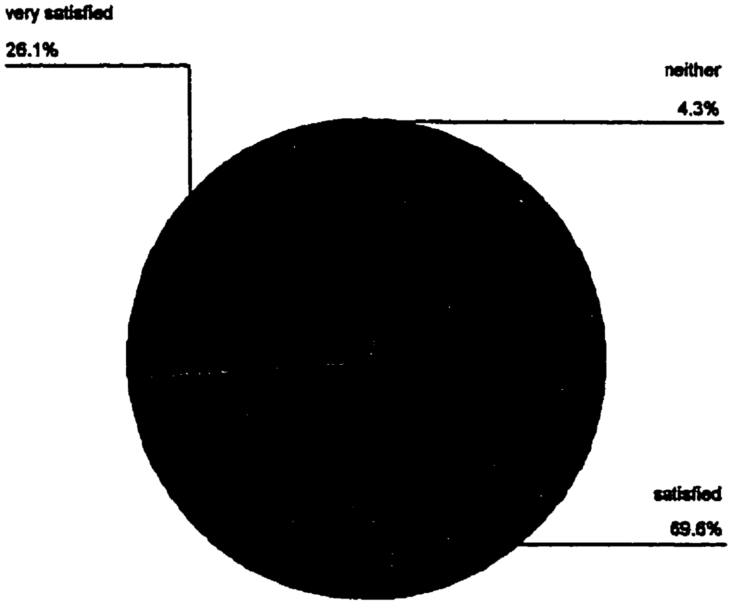
While the majority of care providers were "satisfied" (60.9%) or "very satisfied" (8.7%), three care providers (13%) expressed dissatisfaction with their opportunities for acquiring new skills. The majority of the student respondents were "satisfied" (69.9%) or "very satisfied" (26.1%) with their opportunities for acquiring new skills. Four percent of students were "neither satisfied nor dissatisfied" with their opportunities for acquiring new skills, and there were no assessments of dissatisfaction among students.

Figure 5.12
How satisfied are you with your opportunities for acquiring new skills?

Care Provider



Student



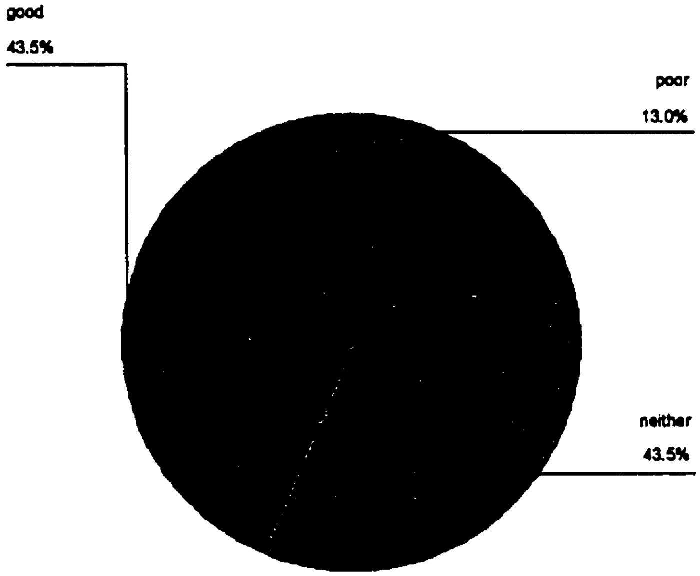
Health and Social Care: Availability and Quality Facet

The Health and Social Care facet "examines the person's view of the health and social care in the near vicinity. 'Near' is the time it takes to get help" ("Division of Mental Health," 1995). Respondents were asked "How would you rate the quality of social services available to you?". Independent t-tests revealed that the mean score for this question was 3.30 for care providers, and 3.91 for students ($t=-3.873$, $p<.000$). Frequency results indicated that care providers rate the quality of social services lower than students (Figure 5.13). Care providers assessed social services as "good" (43.5%) or "neither poor nor good" (43.5%). There were no "very good" ratings from care providers. Three care providers (13%) reported the quality of social services available to them was "poor".

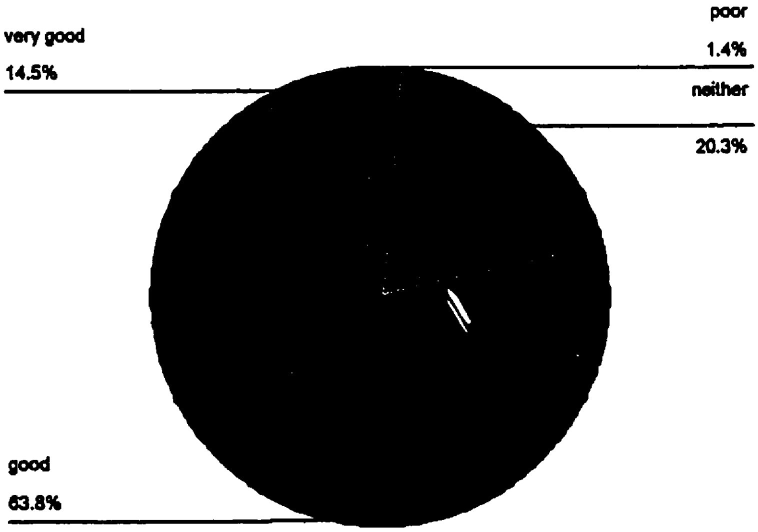
Students gave positive ratings to the quality of social services available to them. The student population rated the quality of social services primarily as "very good" (14.5%) or "good" (63.8%). Fourteen people (20.3%) rated services as "neither poor nor good" and only one individual from the student population indicated the services were "poor" (1.4%).

Figure 5.13
How would you rate the quality of social services available to you?

Care Provider



Student

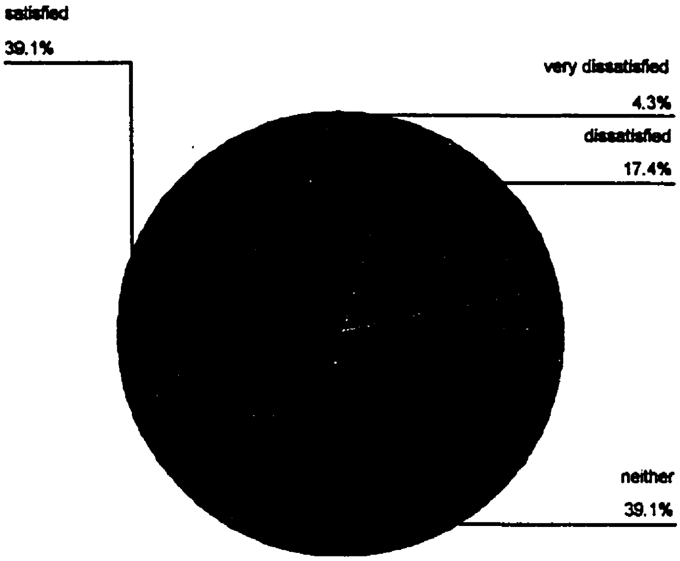


With respect to another Health and Social Care facet question of the environment domain, care providers and students were asked to evaluate "How satisfied are you with the social care services?". Care providers scored significantly lower (M=3.13) than students (M=3.86) when respondents assess their satisfaction with the social care services (t=-3.777, p<.000). Results from frequencies indicated care providers are less satisfied with social care services (Figure 5.14). There were no "very satisfied" care providers, and only nine "satisfied" caregivers (39.1%). Another nine care providers (39.1%) were "neither satisfied nor dissatisfied". Most markedly, four care providers (17.4%) expressed dissatisfaction, and one care provider (4.3%) was "very dissatisfied" with social care services.

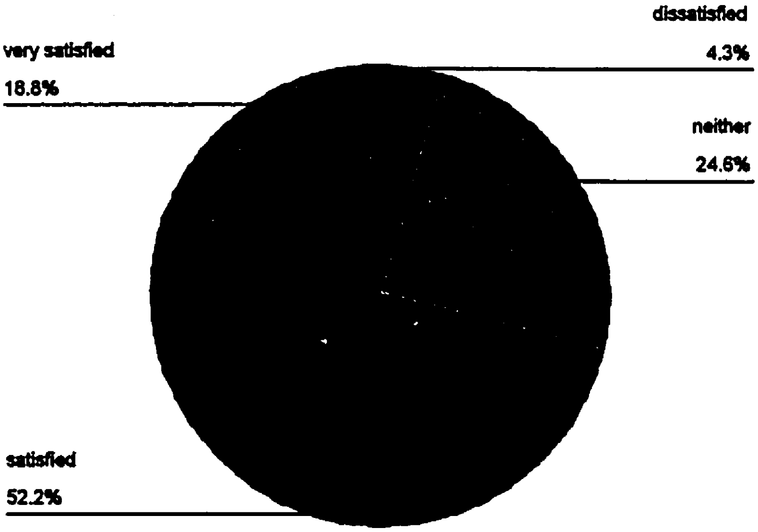
In contrast, 71% of the student population was "satisfied" (52.2%) or "very satisfied" (18.8%) with social care services. One quarter of students (n=17) were "neither satisfied nor dissatisfied", and only three students (4.3%) were "dissatisfied". There were no "very dissatisfied" respondents in the student population.

Figure 5.14
How satisfied are you with the social care services?

Care Provider



Student



Spirituality/Religion/Personal Beliefs Domain

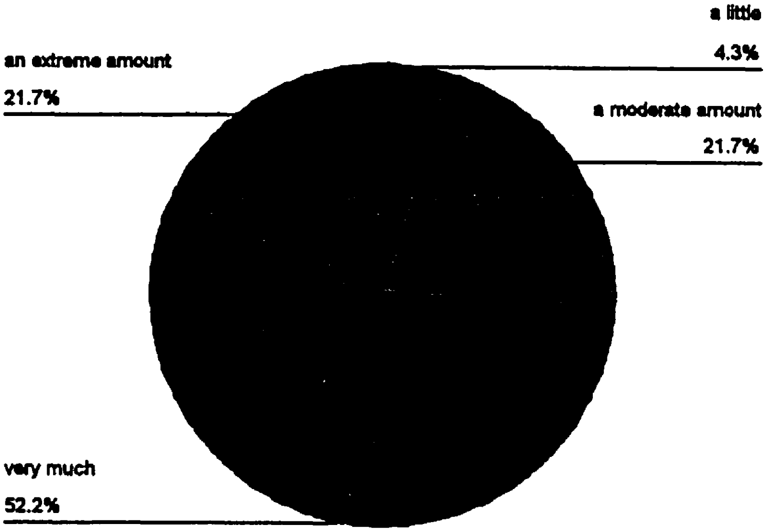
Spirituality/Religion/Personal Beliefs Facet

The Spirituality/Religion/Personal Beliefs facet of the domain by the same name "examines the person's personal beliefs and how these affect quality of life" ("Division of Mental Health," 1995). Respondents were asked to assess "To what extent do you feel your life to be meaningful?" (Figure 5.15). A t-test revealed that care providers scored lower (M=3.91) than students (M=4.28) when asked this question (t=-2.069, p<.041). Frequencies illustrate that the student population felt their lives were meaningful to a greater extent. Five care providers indicated their lives were extremely meaningful (21.7%). Twelve caregivers felt their lives were very meaningful (52.2%), and five expressed their lives were moderately meaningful (21.7%). There was one care provider (4.3%) felt his or her life had little meaning.

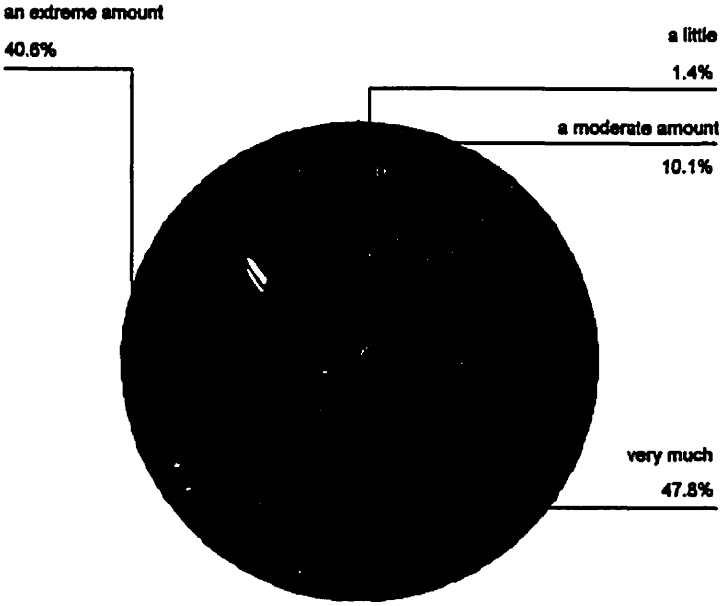
Students provided more positive assessments. Student respondents felt their lives were extremely meaningful (40.6%), very meaningful (47.8%) or moderately meaningful (10.1%). One individual from the student sample (1.4%) reported his or life only "a little" meaningful as well.

Figure 5.15
To what extent do you feel your life to be meaningful?

Care Provider



Student



Overall QOL and Individual Domains

Overall Quality of Life

When considering the association between the overall quality of life and caregiving for people living with HIV or AIDS, the results of a t-test revealed no significant difference. Care providers did not significantly differ from the student population in terms of their evaluation of their quality of life. Quality of life, when calculated as one total score, was assessed slightly higher among students (Mean = 78.44, SD = 14.44) than by care providers (Mean = 72.55, SD = 22.20). Although no average score exists, these scores appear to be relatively high, considering both groups provide average overall quality of life scores that range between 72 to 79 (a completely positive evaluation of quality of life being 100).

Individual Quality of Life Domains

An examination of the individual quality of life domains of the WHOQOL questionnaire revealed no significant differences between care providers and the student population. Six t-tests were utilized to determine whether significant differences existed between the means for individual QOL domains in care providers and the student population. Significant differences between care providers and students were not found, in terms of their evaluations of the physical domain of quality of life score through a t-test. The remaining five domains revealed the similar findings.

An examination of the range, mean and standard deviation of individual quality of life scores revealed trends for care providers and the student population (Table 5.4).

Measures of central tendency and variability were similar for both groups. The range for particular domains demonstrates a simple measure of dispersion (Cherry, 2000). There was an 81-point difference in scores for the spirituality domain, with a range from 19-100 for care providers, and a 75-point difference, with a range from 25-100 for students. Scores for the physical domain ranged from 40-98 for care providers and from 31-98 for students, psychological ranged from 24-96 for care providers and from 45-90 for students, and level of independence ranged from 36-80 for care providers and from 44-80 for students. Social relationship and environment scores also revealed significant ranges: social relationships ranged from 33-92 for care providers and from 27-98 for students, and environment ranged from 48-91 for care providers and from 41-96 for students.

The mean values for individual domains were similar in both groups. For the physical domain, the mean value for care providers was 70.92 (SD=16.20), and the mean value for students was 68.21 (SD=13.61). The mean value was 69.67 (SD=16.06) for care providers and 71.94 (SD=10.09) for students for the psychological domain. The level of independence domain revealed a mean value of 69.72 (SD=10.72) for care providers, and a mean value of 70.88 (SD=7.84) for students. Mean values for the social relationships domain were 66.49 (SD=19.07) for care providers and 73.33 (SD=14.67) for students, and mean values for the environment domain were 71.60 (SD=12.38) for care providers and 73.55 (SD=11.63) for students. For the spirituality domain, the mean value for care providers was 73.10 (SD=18.98), and 79.35 (SD=16.89) for students.

Table 5.4
Range, Mean and Standard Deviation for Individual Quality of Life Domain Scores for Care Providers and Students Combined (n=92)

Domain	Range	Mean	SD
Physical			
Care Provider	58 (40-98)	70.92	16.20
Student	67 (31-98)	68.21	13.61
Psychological			
Care Provider	72 (24-96)	69.67	16.06
Student	45 (45-90)	71.94	10.09
Level of Independence			
Care Provider	44 (36-80)	69.72	10.72
Student	36 (44-80)	70.88	7.84
Social Relationships			
Care Provider	58 (33-92)	66.49	19.07
Student	71 (27-98)	73.33	14.67
Environment			
Care Provider	44 (48-91)	71.60	12.38
Student	55 (41-96)	73.55	11.63
Spirituality			
Care Provider	81 (19-100)	73.10	18.98
Student	75 (25-100)	79.35	16.89

Summary

This chapter presented the results of the study. Tables and reports about descriptive statistics such as frequencies and percentages were used to describe the characteristics of care providers and students, as well as a brief description of the serostatus of care recipients. Descriptive data about particular domain facets were also presented, indicating a number of areas where caregivers provided poor assessments.

Analyses of variance revealed statistically significant facet question scores, indicating care providers perceive a need in several areas within quality of life domains. Findings from analyses of variance examining overall quality of life and individual quality of life domain scores suggested no significant differences. The findings of this chapter and implications will be discussed in the following chapter.

Chapter Six: Discussion and Implications

Introduction

The purpose of this chapter is to discuss the results presented in Chapter Five, and to establish practical and research implications based on the findings of this study. The chapter begins with the consideration of the characteristics of the sample. This is followed by a discussion about individual facet scores that proved to be statistically significant. The results of analyses from overall quality of life results, and the individual quality of life domains are discussed in terms of a lack of significant findings. A number of scenarios are presented that speculate about the lack of significance between care providers and students. The manner through which these results correspond to the quality of life framework selected for this study is then explained. Finally, the chapter concludes with implications of this study for practitioners and researchers.

Characteristics of the Sample

The characteristics collected from this sample illustrate a diverse group of individuals in terms of gender. However this sample is quite similar in terms of age, education and marital status. Care providers were equally represented by males (n=11) and females (n=12). The student population was predominately represented by female respondents (n=58), with only ten male students. This sample of care providers corresponds with many samples in HIV/AIDS caregiving literature where males account for a large percentage of care providers (Pakenham et al., 1995; Turner et al., 1998; Turner & Catania, 1997).

Caregivers indicated they were predominately between 30-49 years of age, while student respondents indicated they were slightly younger with the majority of students citing 20-39 years of age. Again, care providers in this sample echo previous study samples, signifying that care provision is accomplished by individuals who are young in comparison to other caregiving cohorts (Wardlaw, 1994; Penner & Finkelstein, 1998; Turner et al., 1998).

This particular caregiving sample was very well educated. Seventy-five percent of care providers in this study received some form of tertiary education (college, undergraduate, postgraduate). Using a university student comparison sample, students boasted a 100% tertiary education level. As few studies provide information about education levels for care providers of PLWHA generally, it is not known how these results compare with previous samples.

The marital status characteristics followed a similar pattern for both care providers and students: predominantly single, followed by married, and living as married. One slight difference was a larger proportion of married individuals in the student population. Again, few studies in HIV/AIDS caregiving literature investigate the marital status of respondents, and thus it is unknown if these results correspond with previous research.

When asked about their care recipients, care providers reported that the majority of recipients were not newly diagnosed and had moderate to end-stage sickness. Care recipients' year of HIV diagnosis was grouped into three sets. Care providers most frequently indicated that recipients were diagnosed 10-14 years ago (41.7%). A third of recipients were diagnosed 5-9 years ago, and 25% of recipients were diagnosed in the past four years. This indicates a decline in HIV diagnoses in each consecutive cohort of years. As a group, recipients being cared for by the caregivers in this study are not well: forty percent of care recipients were reported to be living with full-blown AIDS, and 47% were HIV-positive with symptomatology.

The most surprising finding from the demographic results of this study was the reported symptomatology of care providers and students. One would expect to find HIV-positive care providers, with a variety of different caregiving types. For example, a care provider who is the care recipient's partner may also have the virus, or a volunteer care provider may choose to volunteer because he or she has HIV as well and wants to help others while able to provide care. However, no care providers in this study reported having HIV-positive status. Surprisingly while there were no seropositive caregivers, there were HIV-positive individuals in the comparison sample of students. Two students reported that they were HIV-positive. This number may actually be higher than reported because 62% of the general population did not answer this question.

There is an important implication of this demographic result for the overall results of this study. A research study consisting of care providers with HIV or AIDS could potentially diminish the quality of life scores of the care provider sample. In addition, a general population consisting of no seropositive respondents could serve to increase the average quality of life score of the comparison sample. In other words, the addition of seropositive care providers and seronegative students could reveal lower QOL scores for care providers. Such differences in the samples could reveal additional significant differences in quality of life scores. Thus, the implication of this demographic result is that significant differences that may exist were not present in this study, due to the sample characteristics.

Individual Quality of Life Facets

Several individual quality of life facets revealed statistically significant results. Caregivers provided negative assessments for one general quality of life question, three environment domain questions, and one spirituality/religion/personal beliefs question. Care providers rated their quality of life lower than students did (8.7% rated their QOL as poor, while no students rated their QOL as poor). Of four general quality of life questions, this was the only one that showed a statistical difference. Nevertheless, a poor rating for quality of life in general terms signifies that care providers contend with issues that prevent a positive assessment of QOL. Low scores on other statistically significant questions by care providers indicate areas where quality of life is diminished.

Care providers were not satisfied with their abilities to acquire new skills. The intensity of the caregiving commitment is one explanation for this dissatisfaction. Folkman (1997) described care providers as being "on call" 24 hours a day. In addition to a significant time commitment, there are a variety of habitual tasks for the care provider to fulfill (McCann & Wadsworth, 1992; Wardlaw, 1994; Stujduhar & Davies, 1998). It is understandable that care providers are not satisfied with their opportunities to acquire new skills, since they are often occupied with the demands of an individual with medical, psychological, social, or practical needs. The taxing demands of the care recipient can lead care providers to neglect their own needs (Ruppert, 1996).

There were also two individual quality of life facet questions from the Health and Social Care facet with statistically significant results. The first question asked "How would you rate the quality of social services available to you?". Lippman et al. (1993) note that "the physical and mental health of the patient, and the emotional stability of their significant others depend greatly on the quality of these holistic services" (p.77). Care providers rated the quality of social services available to them (13% rated the quality as poor) lower than students (1.4% rated the quality as poor). In addition to the poor evaluations within the facet questions, in the general comment section following the questionnaire, one care provider wrote:

> When I was with my first buddy, he was forbidden to attend the social services office because of his disease. It was like hitting a brick wall. Perhaps for you next thesis you might examine attitudes in social workers which so frequently impede the progress of those we care for and love.

The stigma and social isolation endured by many care providers is well documented (Lippmann et al., 1993; Reynolds & Alonzo, 1998). This is potentially one of the contributing factors to their negative evaluation of social services. Care providers clearly have negative opinions about the social services available to them.

The second question that revealed a significant difference between care provider and student scores was "How satisfied are you with the social care services?". Again, caregivers indicated dissatisfaction through negative evaluations (22% indicated they were very dissatisfied or dissatisfied with social care services). Care providers are often the "navigators" of social care services for the care recipient (Stujduhar & Davies, 1998). This would make them acutely aware of their value. Care providers may also use support groups or counselling themselves (LeBlanc et al., 1995). Their assessment of the quality of, and satisfaction with social care services is important, because such services are essential to the care provider; for PLWHA they are caring for and caregivers themselves.

The literature cites care provider problems with health and social care workers. For example, care providers complain they often do not feel heard by professional care providers, and have to work even harder to obtain comfort for their loved one (Stujduhar & Davies, 1998). Care providers berate health and social service systems as rigid, impersonal and demeaning systems that diminish caregivers' experience (Stujduhar & Davies, 1998). In addition, caregivers are frustrated with the red tape and refusing eligibility requirements for programs and services (Wardlaw, 1994), and feel humiliated asking for money to pay for basic care expenses (Stujduhar & Davies, 1998). Services perceived as culturally or ethnically insensitive were particularly cited as barriers (Wardlaw, 1994). There is a perception among care providers that they experience problems accessing services when they need them the most (Stujduhar & Davies, 1998).

With respect to support offered to care providers, caregivers indicate support groups are not adequate to meet their needs (Cowles & Rodgers, 1991). Other care providers lack the knowledge that such groups are even available (Wardlaw, 1994). Rosengard and Folkman (1997) write "The extent to which caregivers feel supported is influenced by their perception of the availability and adequacy of social support in material, emotional, and practical areas" (p.382). Thus, care providers who perceive they are adequately supported will feel unsupported. Clearly those perceptions exist for the care providers in this study.

When care providers were asked why they thought health and social care providers were not supportive, care providers cite heavy workloads, few opportunities for debriefing stressful work incidents, and health care providers' fear of working with PLWHA (Stujduhar & Davies, 1998). Furthermore, care providers speculate that professionals lacked a supportive manner with caregivers and recipients, because they felt unsupported themselves in their own work environments (Stujduhar & Davies, 1998).

A substantial amount of information about health and social care workers and HIV/AIDS exists (for example, Miller, 1995; Ferrari, McCown & Pantano, 1993; McCann, 1997). The majority of literature documents the incredible stress and burden of providing care in the HIV/AIDS environment (Wade & Perlman Simon, 1993; Miller, 1995; Gordon et al., 1993). Health and social care workers have stresses related to caring for dying patients/clients who are young, and were a previously healthy population, concerns about safety (Wade & Perlman Simon, 1993), and emotional identification with patients/clients and their care providers (Gordon et al., 1993). There are a variety of apparent stresses for health and social care providers.

The literature thus, details the dissatisfaction of care providers with health and social care services as well as the stresses for health and social care workers. The disenchantment of both lay and professional care providers effectively causes a split whereby professionals can become disillusioned, distressed and distant (Gordon et al., 1993), while lay care providers can become frustrated, angry and overwhelmed (Wardlaw, 1994; Stujduhar & Davies, 1998).

Despite the poor ratings of several care providers, approximately 40% of care providers rated the quality of social services available to them as “good”, and approximately another 40% rated their satisfaction as “neither poor nor good”. In addition, care providers indicated they are “satisfied” (39.1%) or “neither satisfied nor dissatisfied” (39.1%) with the social care services they receive. These results are encouraging, as they indicate that many care providers are satisfied with the social care services they receive, or are neutral. This suggests that a number of social care services are serving their consumers well, and providing adequate social care to consumers.

Finally, care providers scored significantly lower than students when asked “To what extent do you feel your life to be meaningful?”. The mean score of care providers was 3.91, and the mean score for students was 4.28. One individual indicated his/her life had little meaning. This is not a common research question, and thus cannot be compared with other research studies. In contrast to some other facet question responses that have direct practical implications, this broad facet could encompass a variety of issues that could be practically significant. For example, LeBlanc et al. (1995) explain that AIDS caregivers are in great need of emotional support; they face chronic stress and experience expressive symptomatology. Care providers commonly feel overwhelmed, fatigued, and exhausted (Ruppert, 1996). Perhaps such consequences of caregiving are responsible for a diminished sense of a meaningful life.

Students did score significantly lower than care providers when asked “How easily do you get tired?” (20% of students get tired very to extremely easily, compared to 8.6% of care providers). One would expect that care providers would evaluate this question negatively as well. Considering the workload, deadlines and stresses involved in university education, however, this finding is not surprising.

The results from the individual facet questions are meaningful because this type of quality of life information is not found elsewhere in the literature. These results reveal areas where care providers perceive a need and require more attention. The implications of these findings are described following the discussion about overall quality of life and individual quality of life domains.

Overall Quality of Life and Individual Domain Scores

No significant differences were found between care providers and students in terms of overall quality of life. Overall QOL was not of primary interest however, as WHOQOL assessment instructions caution that the examination of individual domain scores is the preferred method of investigating results (Division of Mental Health, 1995c).

Significant differences were not found within individual quality of life domain scores. A series of t-tests revealed no significant differences between care providers and students in terms of individual quality of life domains. This study was the first of its kind, so there is no previous research with which to compare this study. However, considering the number of issues and stresses associated with providing care to someone with HIV or AIDS, these results appear to be contrary to the literature.

There were a substantial number of responses supplied for each of the questions asked in the WHOQOL. The ranges and standard deviations within individual domains were large. For example, there was an 81-point range between the highest and lowest spirituality scores (19-100) for care providers and a 75-point range (25-100) for students. The large standard deviations indicate a high degree of variability exists between scores in each of the six quality of life domains. In other words, scores of respondents in this study were very different. These tools of analysis illustrate the diversity of responses collected from care providers of people living with HIV or AIDS and the general population.

Care Provider Quality of Life

With the myriad of issues that care providers contend with, one might speculate that care provider quality of life would be diminished or at least challenged by providing care to someone with HIV or AIDS. Results from this study indicate that there are several individual quality of life facet questions that care providers assessed lower, but on a broader level, there were no statistically significant differences between care providers and students in terms of quality of life.

There are a variety of scenarios to explain why these results did not reveal statistically significant differences. The results were contrary to what one would expect, given the number of caregiving studies in literature. The following section illustrates a number of reasons why these results may differ from other research in the care provision arena.

The Importance of Positive Aspects of QOL

The literature addresses the positive aspects of caring for someone with HIV or AIDS to a small extent (Reynolds & Alonzo, 1998; Clipp et al., 1995; Folkman, 1997; Brown & Powell-Cope, 1991). Perhaps the importance of positive aspects of caring is even more substantial than the literature acknowledges. Individuals are often able to find strength through difficult life experiences, and make positive evaluations of their quality of life (Wardlaw, 1994; Folkman, 1997).

For example, Friedland et al. (1996) demonstrated that despite their HIV-positive diagnoses, many PLWHA in Toronto, Ontario gave positive QOL evaluations. Although this example considers HIV-positive individuals, one can extrapolate that if a PLWHA can assess their quality of life positively, care providers have the potential for positive quality of life assessments as well. The literature discusses the negative consequences of caregiving in great detail, yet often neglects to report about how remarkably individuals can adjust to, and succeed in the care provision role. The results of this study indicate that positive aspects of care provision require deeper exploration.

Students are a Unique Population

The comparison sample may not be truly representative of the general population, and this is another possible explanation for lack of significance between care providers and the general population. Students are a unique group. In this study for example, two of the individuals in the Social Work Faculty were HIV-positive, which could potentially impact the outcome of the results. If care providers could be compared with a genuine, representative, general population sample, significant differences may be found that were not in this study.

Social work students may be drawn to the profession for a number of reasons, including their need for self-examination. The social work profession attracts a significant proportion of students with personal experiences of psychosocial trauma and oppression, including various forms of abuse (Barter, 1997). As the program may attract those students who want to sort through personal issues, students are at risk of scoring lower than an "average" person on a number of quality of life domains.

The social work profession educates students to become introspective, conscious of their thoughts, feelings and reactions, and to critically examine their inner selves. Care providers who are not immersed in such an environment may be less likely to critically appraise their environment or selves. This may be another contributing factor to similar scores between groups. With the same awareness as the social work students, perhaps care providers would give additional lower ratings to their quality of life. Immersing oneself in an environment where beliefs, understanding, perceptions and feelings are constantly challenged may alter ones self-assessment of quality of life.

Quality of Life Framework

The quality of life framework utilized for this study illustrated quality of life in terms of a quality of life field, containing the "quality of life outcome circle", the "quality of life determinants circle", the "moderating conditions ellipse" and feedback loops connecting each part (Rootman and Raeburn, 1998). All of these component parts of the QOL field interact in a complex sphere "made up of many parts and processes" (Rootman and Raeburn, 1998).

The results from this study fit very well with the quality of life framework selected. Although the six domains of quality of life identified in the WHOQOL do not correspond directly with the quality of life components of the framework, the QOL outcome circle encompasses each of the six WHOQOL domains. The framework explicitly describes physical, psychological, spiritual and social sub-components (or domains) of quality of life. The remaining two domains are consumed in the Becoming and Belonging components of the quality of life outcome circle. The ecological, community and personal growth sub-components in the framework correspond to the environment domain of the WHOQOL. The practical and leisure sub-components of the framework correspond with the level of independence domain of the WHOQOL.

It is apparent from the results that care providers are not satisfied with the social services available to them, or their opportunities for acquiring new skills. These negative results emerged in the environment domain of the WHOQOL. If one was to position these results into the quality of life field described in the framework, they would be placed into the quality of life determinants circle. The negative results (social services and opportunities for acquiring new skills) would be called environmental determinants, and could be viewed as both macro (spheres beyond self) or immediate (close to everyday lives) determinants.

Rootman and Raeburn (1998) indicate that quality of life is viewed as being the result of identifiable determinants. The key to transforming negative determinants to positive determinants of quality of life is to look at the moderating conditions ellipse. This is where practical assistance from social workers and other practitioners, resources, and supports exist. Negative determinants can be moderated by these variables, which in turn will impact one's quality of life.

For example, if one was to improve the quality of social services by initiating a successful support group for care providers of PLWHA, QOL could be moderated in a positive direction. The environmental determinants (social services) would become positive determinants, and this would "feedback" into the care provider's quality of life outcome circle. This in turn would possibly change a caregiver's assessment of how they would rate quality of life, thereby effectively improving quality of life through changes in the environment.

Therefore, the framework provides a manner of explaining how quality of life exists currently, as well as how quality of life can be improved for care providers of people living with HIV or AIDS in practical terms.

Implications

Practical Implications

There are several practical and research implications arising from this study about the quality of life of care providers of PLWHA. The results of the individual facet questions with statistically significant differences have important implications for care providers of people living with HIV or AIDS, and the social workers and other practitioners providing services to them. The results of social service questions (from the Health and Social Care facet) indicate a need for improvement in the social service arena. Practitioners have a responsibility to care providers, to determine their needs, and to assist caregivers accordingly.

The social service arena is key: from this starting point, care providers may satisfy other areas that were negatively assessed using the WHOQOL. Social services themselves require changes, according to the assessment by care providers. Yet, within social services, the other facet questions revealed to be lower could be addressed. For example, social workers could assist care providers to increase their opportunities to acquire new skills. Such changes in the care provider's environment domain may increase the provider's ratings of their quality of life, and the meaningfulness of their life. Changes can be made, and support provided, on a number of levels. These levels of assistance are discussed in the following paragraphs.

Clinical Level

Social workers can focus on three main objectives in clinical practice: providing information, bolstering supportive ties, and leading support groups (Jankowski, Videka-Sherman & Laquidara-Dickinson, 1996; Walker et al., 1996). Social workers can provide a context where care providers can meet each other, develop supportive relationships and feel empowered (Turner et al., 1998; Getzel, 1991). A number of support groups with care providers of people with HIV or AIDS boast positive evaluations from participating care recipients (Crandles et al., 1992; Goicoechea-Balbona, 1997; Hansell et al., 1998). Such groups should continue to support care providers in instrumental and expressive ways, as identified by caregivers.

Community Level

Continuity and completeness of care is another important element that needs to be integrated into practice. The care providers in this study indicated they are not satisfied with health and social services they receive. Many researchers have called for an increased effort to successfully and completely provide caregivers with this resource. Researchers appeal to health and social service practitioners to develop relationships with care providers (Reidy et al., 1991), and to advocate on their behalf (Lippmann et al., 1993). They also speak to the importance of considering care providers as part of the health care team and restructuring care delivery systems to ensure the best fit between resources, the patient and the care provider (Stajduhar & Davies, 1998; Schofield et al., 1996).

The structure of services is paramount. Wardlaw (1994) emphasizes the importance of adapting and even transforming, support services to fit the needs of care providers, as these needs may change repeatedly over time. Expectations for professionals to be knowledgeable about HIV/AIDS and local resources and services are also cited (Wardlaw, 1994). Finally, professionals should be mindful that keeping "an open mind and heart, as always, are the most effective intervention tools" (Wardlaw, 1994, p.382). Such actions would undoubtedly increase the health and social service assessments made by care providers, thereby increasing positive quality of life assessments.

Policy Level

Education should be directed at policy makers, politicians and the general public, about the dissatisfaction care providers have with particular areas of quality of life discovered in this study, and the general range of issues care providers contend with. There is a also need for research in a number of related areas in order to advocate to policy makers and service providers that care providers require various types of support in their journey with the HIV-positive care recipient.

Education also needs to be directed at social workers and other health and social service providers specifically to increase the knowledge, and decrease the stereotypes and stigma attached to HIV/AIDS. Misconceptions and ignorance surrounding this disease can cripple people living with HIV or AIDS, their care providers, and their support networks. As Peterson (1991) states, "Only if social workers are knowledgeable about the range and impact of this disease will they be able to educate their clients, colleagues, and communities effectively" (p.32). AIDS is not restricted to a certain population, or certain agencies or communities. All social workers are responsible for understanding the issues for recipients and care providers, and for discovering methods to bolster positive quality of life assessments from those touched by the AIDS epidemic.

Research Implications

This study did not generate statistically significant findings for quality of life overall, or for individual quality of life domains. Many questions surrounding quality of life in care provision of PLWHA remain. However, one conclusion from this study can be drawn: this research area is gravely underdeveloped. Further exploratory research that examines individual domains and facets of quality of life is recommended, in order to advance the understanding of quality of life and care providers of people living with HIV and AIDS. Quality of life assessments provide an encompassing view of an individual's satisfaction with life, and within a variety of areas of an individual's life. Such assessments are truly invaluable from research and clinical perspectives.

There are two implications for study parameters from this research. Research with specific care provider populations would help to clarify if specific caregiving groups are more vulnerable to negative aspects of care provision. The utilization of respondents in which each sample of individuals represents only one relationship to the care recipient (for example family members) would provide valuable information about several groups of caregivers. Secondly, this study utilized a relatively small sample of caregivers, and thus had limited statistical power. Future studies using larger samples would have a greater ability to detect statistically significant differences if they existed. Larger samples of care providers would also impart greater generalizability of findings to researchers.

Another implication of this study for researchers is the recognition that the focus needs to be on those positive aspects that enhance a caregiver's quality of life, in addition to the issues that can diminish a care provider's quality of life. Highlighting the successes of caregivers, in addition to revealing problems areas, is also important for practitioners who support care providers of people living with HIV or AIDS. "Building on success" and reinforcing positive events and ideas can be an intervention target, to improve QOL in care providers. Increasing caregiver quality of life to a greater extent has the potential to assist the care provider, as well as to inadvertently assist the care recipient.

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Appendix A: Letters of Consent

Consent Letter for Caregivers

Research Project Title: "Quality of Life of Caregivers of People with AIDS"

Investigator: Pamela Cameron, BSW (MSW Student)

YOUR PARTICIPATION IN THIS STUDY IS COMPLETELY VOLUNTARY

This letter of consent explains the purpose of this research study. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Please take the time to read this form carefully, and ask any questions you may have before completing the questionnaire.

1. **Purpose and Usefulness**: The purpose of this study is to learn about how caregivers of people with AIDS evaluate their quality of life. The results of this study will be used to help identify the types of supports and services that may be helpful for caregivers of people with AIDS.
2. **Participants, Procedures and Your Participation**: I am asking for your participation in this study because you are the primary caregiver of someone with AIDS. You will be asked to complete a 100-question questionnaire about your quality of life.
3. **Research Design**: I will be comparing your responses with the responses given by a sample of the general population in order to understand how caregivers' quality of life differs from the general population.
4. **Risks/Costs/Benefits**: This research does not pose risks to anyone who will be participating in the study. The only cost to you is the time that it will take in order to complete the questionnaire (about one hour). There will be no monetary compensation. This agency has agreed to arrange counselling services to anyone completing this questionnaire that requests counselling.
5. **Assistance**: If you would like any assistance in reading or completing the questionnaire, a staff member or I will be able to help you.
6. **Confidentiality**: When completing the questionnaire, you will not be asked to include your name. Demographic information (for example, your birth date and education

level) is included in this questionnaire, but will not identify individual participants. Your completed questionnaire and demographic information will be stored on computer, in my secure and private office. Because there is no identifying information on the questionnaires, no one will be able to connect which answers were provided by which participants.

7. **Further Information**: Your participation in this study will be finished when you have completed the questionnaire. You are encouraged to ask me or another staff member any questions about the study you may have. A copy of the results of this study will be available for you at this agency once I have completed the study.

Your completion of this questionnaire indicates that you have understood to your satisfaction the information regarding participation in the research project, and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator from her legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Pamela Cameron, Faculty of Social Work, University of Calgary at (403) 284-9468. (This is my home number)

If you have any questions concerning your participation in this project, you may also contact my supervisor, Dr. J. Sieppert at (403) 220-6983.

THANK YOU FOR YOUR HELP

Consent Letter for General Population

Research Project Title: "Caregivers of People with AIDS"

Investigator: Pamela Cameron, BSW (MSW Student)

YOUR PARTICIPATION IN THIS STUDY IS COMPLETELY VOLUNTARY

This letter of consent explains the purpose of this research study. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Please take the time to read this form carefully, and ask any questions you may have before completing the questionnaire.

1. **Purpose and Usefulness:** The purpose of this study is to learn about how caregivers of people evaluate their quality of life, as compared to the general population. The results of this study will be used to help identify the types of supports and services that may be helpful for caregivers of people with AIDS.
2. **Participants, Procedures and Your Participation:** I am asking for your participation in this study as a member of the "general population". You will be asked to complete a 100-question questionnaire about your quality of life.
3. **Research Design:** I will be comparing your responses with the responses given by caregivers of people with AIDS in order to understand how caregivers' quality of life differs from the general population.
4. **Risks/Costs/Benefits:** This research does not pose risks to anyone who will be participating in the study. The only cost to you is the time it will take in order to complete the questionnaire (about one hour). There will be no monetary compensation. Counselling services are available to anyone completing this questionnaire that requests counselling.
5. **Assistance:** If you would like any assistance in reading or completing the questionnaire, I will be able to help you.
6. **Confidentiality:** When completing the questionnaire, you will not be asked to include your name. Demographic information (for example, your birth date and education level) is included in this questionnaire, but will not identify individual participants. Your completed questionnaire and demographic information will be stored on computer, in my secure and private office. Because there is no identifying

information on the questionnaires, no one will be able to connect which answers were provided by which participants.

7. **Further Information:** Your participation in this study will be finished when you have completed the questionnaire. You are encouraged to ask me any questions about the study you may have. A copy of the results of this study will be available for you in the Faculty of Social Work office once I have completed the study.

Your completion of this questionnaire indicates that you have understood to your satisfaction the information regarding participation in the research project, and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator from her legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Pamela Cameron, Faculty of Social Work, University of Calgary at (403) 284-9468.

If you have any questions concerning your participation in this project, you may also contact my supervisor, Dr. J. Sieppert at (403) 220-6983.

THANK YOU FOR YOUR HELP

Appendix B: WHOQOL Questionnaire

Field Trial

WHOQOL-100

February 1995

Instructions

This questionnaire asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

For example, thinking about the last two weeks, a question might ask:

How much do you worry about your health?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

You should circle the number that best fits how much you have worried about your health over the last two weeks. So you would circle the number 4 if you worried about your health "Very much", or circle number 1 if you have worried "Not at all" about your health. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

Thank you for your help

The following questions ask about **how much** you have experienced certain things in the last two weeks, for example, positive feelings such as happiness or contentment. If you have experienced these things an extreme amount circle the number next to "An extreme amount". If you have not experienced these things at all, circle the number next to "Not at all". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all" and "Extremely". Questions refer to the last two weeks.

F1.2 (F1.2.1)* Do you worry about your pain or discomfort?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F1.3 (F1.2.3) How difficult is it for you to handle any pain or discomfort?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F1.4 (F1.2.5) To what extent do you feel that (physical) pain prevents you from doing what you need to do?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F2.2(F2.1.3) How easily do you get tired?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F2.4 (F2.2.4) How much are you bothered by fatigue?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F3.2 (F4.1.3) Do you have any difficulties with sleeping?

None at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F3.4 (F4.2.3) How much do any sleep problems worry you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F4.1 (F6.1.2) How much do you enjoy life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

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* The numbers in brackets refer to the number of the question in the pilot question pool. National versions must be constructed using that same question taken from national version of the pilot questionnaire.

F4.3 (F6.1.4) How positive do you feel about the future?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F4.4 (F6.1.6) How much do you experience positive feelings in your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F5.3 (F7.1.6) How well are you able to concentrate?

Not at all	Slightly	Moderately	Very well	Extremely
1	2	3	4	5

F6.1 (F8.1.1) How much do you value yourself?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F6.2 (F8.1.3) How much confidence do you have in yourself?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F7.2 (F9.1.3) Do you feel inhibited by your looks?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F7.3 (F9.1.4) Is there any part of your appearance which makes you feel uncomfortable?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F8.2 (F10.1.3) How worried do you feel?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F8.3 (F10.2.2) How much do any feelings of sadness or depression interfere with your everyday functioning?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F8.4 (F10.2.3) How much do any feelings of depression bother you?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F10.2 (F12.1.3)To what extent do you have difficulty in performing your routine activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F10.4 (F12.2.4)How much are you bothered by any limitations in performing everyday living activities?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.2 (F13.1.3)How much do you need any medication to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.3 (F13.1.4)How much do you need any medical treatment to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F11.4(F13.2.2) To what extent does your quality of life depend on the use of medical substances or medical aids?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F13.1(F17.1.3)How alone do you feel in your life?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F15.2 (F3.1.2) How well are your sexual needs fulfilled?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F15.4 (F3.2.3) Are you bothered by any difficulties in your sex life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.1(F20.1.2)How safe do you feel in your daily life?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F16.2(F20.1.3)Do you feel you are living in a safe and secure environment?

Not at all	Slightly	Moderately	Very much	Extremely
1	2	3	4	5

F16.3(F20.2.2)How much do you worry about your safety and security?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

*F17.1(F21.1.1)How comfortable is the place where you live?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F17.4(F21.2.4)How much do you like it where you live?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F18.2(F23.1.5)Do you have financial difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F18.4(F23.2.4)How much do you worry about money?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F19.1(F24.1.1)How easily are you able to get good medical care?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F21.3(F26.2.2)How much do you enjoy your free time?

Not at all	A little	Moderately	Very much	An extreme amount
1	2	3	4	5

*F22.1(F27.1.2)How healthy is your physical environment?

Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5

F22.2(F27.2.4)How concerned are you with the noise in the area you live in?

Not at all	A little	Moderately	Very much	An extreme amount
1	2	3	4	5

F23.2(F28.1.4)To what extent do you have problems with transport?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F23.4(F28.2.3)How much do difficulties with transport restrict your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

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* Note: These questions were inappropriately given a capacity response scale in the pilot version. They are to be given an intensity scale in the WHOQOL-100.

The following questions ask about how completely you experience or were able to do certain things in the last two weeks, for example activities of daily living such as washing, dressing or eating. If you have been able to do these things completely, circle the number next to "Completely". If you have not been able to do these things at all, circle the number next to "Not at all". You should circle one of the numbers in between if you wish to indicate your answer lies somewhere between "Not at all" and "Completely". Questions refer to the last two weeks.

F2.1(F2.1.1) Do you have enough energy for everyday life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F7.1(F9.1.2) Are you able to accept your bodily appearance?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F10.1(F12.1.1)To what extent are you able to carry out your daily activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F11.1(F13.1.1)How dependent are you on medications?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F14.1(F18.1.2)Do you get the kind of support from others that you need?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F14.2(F18.1.5)To what extent can you count on your friends when you need them?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F17.2(F21.1.2)To what degree does the quality of your home meet your needs?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F18.1(F23.1.1)Have you enough money to meet your needs?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F20.1(F25.1.1)How available to you is the information that you need in your day-to-day life?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F20.2(F25.1.2)To what extent do you have opportunities for acquiring the information that you feel you need?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F21.1(F26.1.2)To what extent do you have the opportunity for leisure activities?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F21.2(F26.1.3)How much are you able to relax and enjoy yourself?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

F23.1(F28.1.2)To what extent do you have adequate means of transport?

Not at all	A little	Moderately	Mostly	Completely
1	2	3	4	5

The following questions ask you to say how **satisfied, happy or good** you have felt about various aspects of your life over the last two weeks . For example, about your family life or the energy that you have. Decide how satisfied or dissatisfied you are with each aspect of your life and circle the number that best fits how you feel about this. Questions refer to the last two weeks.

G2 (G2.1) How satisfied are you with the quality of your life?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

G3 (G2.2) In general, how satisfied are you with your life?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

G4 (G2.3) How satisfied are you with your health?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F2.3 (F2.2.1) How satisfied are you with the energy that you have?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F3.3(F4.2.2) How satisfied are you with your sleep?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F5.2 (F7.2.1) How satisfied are you with your ability to learn new information?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F5.4 (F7.2.3) How satisfied are you with your ability to make decisions?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F6.3(F8.2.1) How satisfied are you with yourself?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F6.4(F8.2.2) How satisfied are you with your abilities?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F7.4(F9.2.3) How satisfied are you with the way your body looks?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F10.3(F12.2.3)How satisfied are you with your ability to perform your daily living activities?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F13.3(F17.2.3)How satisfied are you with your personal relationships?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F15.3(F3.2.1) How satisfied are you with your sex life?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F14.3(F18.2.2)How satisfied are you with the support you get from your family?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F14.4(F18.2.5)How satisfied are you with the support you get from your friends?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F13.4(F19.2.1)How satisfied are you with your ability to provide for or support others?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F16.4(F20.2.3)How satisfied are you with your physical safety and security?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F17.3(F21.2.2)How satisfied are you with the conditions of your living place?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F18.3(F23.2.3)How satisfied are you with your financial situation?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F19.3(F24.2.1)How satisfied are you with your access to health services?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F19.4(F24.2.5)How satisfied are you with the social care services?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F20.3(F25.2.1)How satisfied are you with your opportunities for acquiring new skills?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F20.4(F25.2.2)How satisfied are you with your opportunities to learn new information?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F21.4(F26.2.3)How satisfied are you with the way you spend your spare time?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F22.3(F27.2.1)How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness)?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F22.4(F27.2.3)How satisfied are you with the climate of the place where you live?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F23.3(F28.2.2)How satisfied are you with your transport?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

F13.2(F17.2.1)Do you feel happy about your relationship with your family members?

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very happy
1	2	3	4	5

G1(G1.1) How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F15.1(F3.1.1) How would you rate your sex life?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F3.1(F4.1.1) How well do you sleep?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F5.1(F7.1.3) How would you rate your memory?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

F19.2(F24.1.5)How would you rate the quality of social services available to you?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

The following questions refer to **how often** you have felt or experienced certain things, for example the support of your family or friends or negative experiences such as feeling unsafe. If you have not experienced these things at all in the last two weeks, circle the number next to the response "never". If you have experienced these things, decide how often and circle the appropriate number. So for example if you have experienced pain all the time in the last two weeks circle the number next to "Always". Questions refer to the last two weeks.

F1.1 (F1.1.1) How often do you suffer (physical) pain?

Never 1	Seldom 2	Quite often 3	Very often 4	Always 5

F4.2 (F6.1.3) Do you generally feel content?

Never 1	Seldom 2	Quite often 3	Very often 4	Always 5

F8.1 (F10.1.2) How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

Never 1	Seldom 2	Quite often 3	Very often 4	Always 5

The following questions refer to any "work" that you do. Work here means any major activity that you do. This includes voluntary work, studying full-time, taking care of the home, taking care of children, paid work or unpaid work. So work, as it is used here, means the activities you feel take up a major part of your time and energy. Questions refer to the last two weeks.

F12.1 (F16.1.1)Are you able to work?

Not at all 1	A little 2	Moderately 3	Mostly 4	Completely 5

F12.2 (F16.1.2)Do you feel able to carry out your duties?

Not at all 1	A little 2	Moderately 3	Mostly 4	Completely 5

F12.4(F16.2.1)How satisfied are you with your capacity for work?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

F12.3(F16.1.3)How would you rate your ability to work?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5

The next few questions ask about **how well you were able to move around**, in the last two weeks. This refers to your physical ability to move your body in such a way as to allow you to move about and do the things you would like to do, as well as the things that you need to do.

F9.1(F11.1.1) How well are you able to get around?

Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5

F9.3(F11.2.2) How much do any difficulties in mobility bother you?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5

F9.4(F11.2.3) To what extent do any difficulties in movement affect your way of life?

Not at all 1	A little 2	A moderate amount 3	Very much 4	An extreme amount 5

F9.2(F11.2.1) How satisfied are you with your ability to move around?

Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very satisfied 5

The following few questions are concerned with your personal beliefs, and how these affect your quality of life. These questions refer to religion, spirituality and any other beliefs you may hold. Once again these questions refer to the last two weeks.

F24.1(F29.1.1)Do your personal beliefs give meaning to your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F24.2(F29.1.3)To what extent do you feel your life to be meaningful?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F24.3(F29.2.2)To what extent do your personal beliefs give you the strength to face difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

F24.4(F29.2.3)To what extent do your personal beliefs help you to understand difficulties in life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

Appendix C: Demographic Questions

ABOUT YOU

What is your gender? Male _____
Female_____

What is your date of birth? _____/_____/_____
Day/ Month/ Year

What is the highest education you have received?
Primary school _____
Secondary school _____
University/College _____
Post-graduate _____

What is your marital status?
Single _____
Married _____
Living as married _____
Separated _____
Divorced _____
Widowed _____

When did the person you are caring for test positive for the AIDS virus?

_____/_____/_____
Day/ Month/ Year

Is he/she currently (Check the category that applies to the person you care for):

HIV-positive, without symptomatology _____?
HIV-positive, with symptomatology _____?
With Full-blown AIDS _____?

Have you tested positive for the AIDS virus? Yes _____
No _____

If Yes, are you currently (Check the category that applies to you):

HIV-positive, without symptomatology _____?
HIV-positive, with symptomatology _____?
With Full-blown AIDS _____?

Do you have any other comments about this questionnaire?

THANK YOU FOR YOUR HELP

Appendix D: Facet Questions

WHOQOL Domains and Facets

Overall Quality of Life and General Health

Domain One – Physical Domain

1. Pain and discomfort
2. Energy and fatigue
3. Sleep and rest

Domain Two – Psychological Domain

1. Positive feelings
2. Thinking, learning, memory and concentration
3. Self-esteem
4. Bodily image and appearance
5. Negative feelings

Domain Three – Level of Independence

1. Mobility
2. Activities of daily living
3. Dependence on medication or treatments
4. Working capacity

Domain Four – Social Relationships

1. Personal relationships
2. Social support
3. Sexual activitiy

Domain Five – Environment

1. Physical safety and security
2. Home environment
3. Financial resources
4. Health and social care: availability and quality
5. Opportunities for acquiring new information and skills
6. Participation in and opportunities for recreation/leisure
7. Physical environment: (pollution/noise/traffic/climate)
8. Transport

Domain Six – Spirituality/Religion/Personal Beliefs

1. Spirituality/religion/personal beliefs