COPING AND “REPLENISHMENT” IN AIDS SOCIAL WORK: VOICES OF PRACTITIONERS

by

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A dissertation submitted to the Graduate Faculty in Social Welfare
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy, The City University of New York
2004

UMI Number: 3115300

ProQuest Information and Learning Company
300 North Zeeb Road
P.O. Box 1346
Ann Arbor, MI 48106-1346

This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

January 14, 2004
Date

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Abstract

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This qualitative research dissertation will describe job-related stressors in AIDS social work and explore the types of coping strategies or organizational supports which exist to buffer stress and to avoid burnout. The term "replenishment" is used to describe the process of coping effectively to avoid becoming depleted from these work stressors.

The research was conducted at seven different designated AIDS Centers in New York City. Using a grounded theory methodology, nineteen social workers were interviewed to determine what job-related stressors impacted job satisfaction and workers' ability to effectively cope. Understanding the role of the organization, and its formal and informal support mechanisms which help staff replenish themselves, was the focus for this study.

Results from the study indicate the positive impact of formal and informal support systems. The personal and professional rewards of AIDS social work, i.e. helping patients and their families, were found to be a major source of staff replenishment. Additionally, AIDS social workers developed a range of self-care techniques to maintain their physical and mental well-being. Finally, future implications for research, administration and education related to the concept of replenishment will be discussed.

Acknowledgments

I sometimes wonder how many people it takes to complete one dissertation. There were so many wonderful and loved family and friends, colleagues and mentors, who contributed to my research and helped me make this a reality.

Much of my inspiration for this dissertation came from my own work in HIV/AIDS. Witnessing the courage and fortitude of people living with this disease has always made me wonder where they got their strength. Also, having the opportunity to work with so many social workers and health care workers, some who have been there from the beginning of the epidemic, makes me feel proud to have been a part of that experience. I would like to thank them for participating in my research and helping me to formulate the concept of replenishment.

I am particularly grateful to Irwin Epstein who, with his gentle persistence and many contributions, from formulating my research to its completion, was and remains a valued advisor, mentor and friend. I am indebted to him for his wisdom, humor and guidance. Also, my committee was extremely helpful in their continued efforts to "make this soup". Nancy Beckerman, with her expertise in AIDS, significantly contributed to my research and dissertation and to Millie Mailick for her insights and willingness to be there to the very end. Thanks, also, to Gary Mallon who was truly there from the beginning as a classmate and at the end as a valued committee member.

The support of family and friends has meant a great deal to me and has always helped me to stay centered. A special thanks to JoAnn, who has been a wonderful sister, mother, best friend and dissertation cheerleader. To Sue, who deserves special recognition for loving me just the way I am. I could not have done this without both of you.

Thanks also to the many friends and colleagues at the University of Michigan Hospital and School of Social Work; Mary Ann, Diane, Pat, Deb, Laura and the social work management team for supporting me through this arduous process. Thanks to Joan Hutchinson for her special talents. Also special thanks goes to Ellen Simon for her many years of friendship and mentoring and who tried every trick in the book to get me to "just do it".

This dissertation is dedicated to my father and mother and Aunt Mary who always believed in the value of a good education, and in me.

They would be proud.

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CHAPTER I

INTRODUCTION AND RESEARCH GOALS

> Sometimes I wonder why I'm still doing this work.
> I wonder if my ears are big enough to hear what I
> need to hear. . . to hear their stories and to have
> a fresh, hopeful place to be with them.
> Quote from an AIDS social worker

Introduction

Acquired Immune Deficiency Syndrome (AIDS) has dramatically impacted the health care system and health care providers as well. Although researchers have documented job-related stressors experienced by AIDS health care professionals (Oktay, 1992; Ross, 1993), few studies have focused on specific factors which contribute to burnout. More importantly, researchers have yet to address methods which social service providers can use to mitigate these factors in caring for patients with AIDS (Cushman, Evans, & Namerow, 1995).

Nonetheless, there is a body of descriptive research on stress and burnout among AIDS health care workers (Egan, 1993; Oktay, 1992). Less studied and understood are the effects of AIDS-related stressors and the individual and organizational coping strategies which help to reduce stress and to replenish AIDS social workers.

Moreover, the concept of *replenishment* has not been utilized heretofore in the social work literature. According to Webster's Dictionary, the word "replenishment" means "to make full or complete again". Viewed as the opposite of depletion (i.e., "to use up or to empty wholly or partly"), replenishment emphasizes active efforts at restoration rather than mere sustenance or survival. An alternative concept frequently used in the literature is "resilience", which, according to Webster's implies springing back into shape or position. When this term has been applied in research, it often referred to a relatively static quality of the individual, such as personal fortitude. By contrast, replenishment describes a more fluid process of first being depleted, then using some type of personal and/or environmental resource to become whole again. As a result, replenishment involves both internal (i.e., resilience) and external (i.e., informal social, and formal/organizational) resources.

Research Goals

One goal of this research was to define and understand replenishment as it relates to coping effectively with job-related stressors. AIDS social workers can become depleted, but this does not necessarily lead to burnout. This research sought to examine the forms of coping which social workers use in order to avoid burnout and to be replenished. Additionally, the study examines whether there is a continuum of coping, ranging from burnout to replenishment. The study uses qualitative interviews to describe emergent themes that help provide a better understanding of this process.

Even in the care of a disease such as AIDS, where emotional exhaustion is well documented (Ross, 1993; Schoen, 1992; Wiener & Siegel, 1990), research describing social workers' coping or replenishment strategies is severely lacking. While there is literature describing various types of formal and informal social supports (Scherr, 1995; Wade & Simon, 1993), these reports fall short in documenting whether organizational supports offered to staff enhance their ability to cope.

This study focused primarily on social workers working in AIDS Designated Centers (ADC) in New York City. Through a descriptive qualitative analysis, I examined the stressors experienced by AIDS social workers, what types of formal and informal support structures existed in the ADCs, and how individual social workers coped. This research was also used to identify interventions that have developed as spontaneous or planned support mechanisms within the organization to help staff cope with the stressors inherent in AIDS work. Interviews for this research study were completed in 1999; therefore, findings reflect the practitioners' responses from that time.

Finally, in this research, I report the expressed needs of AIDS social workers and discuss how organizations can design programs to address these needs. Understanding how AIDS social workers successfully cope with job stressors, and how they can be replenished, in order to remain in this field, is essential for AIDS organizations, direct care staff and patients and families. The findings of this study have important implications as well for ADCs, hospitals, social service providers, administrators, and planners.

As organizations downsize or reengineer in an attempt to maintain fiscal stability, they need to retain experienced, well-trained staff that can provide quality, cost-effective care. Given the complexity of care, shrinking health care dollars, fear of occupational exposure, and the unrelenting psychological stress, staff recruitment and retention become critical issues.

In the subsequent chapters, the qualitative findings from interviews with nineteen AIDS social workers in seven New York City AIDS Centers were used to study the processes of coping and replenishment. This research will describe how job expectations, depending on whether they are fulfilled or not, can impact job-related stress and job satisfaction for AIDS social workers. Additionally, I will discuss what social workers identified as their high and low points in AIDS work, and what role the high points played in helping them cope with their stress. Furthermore, the findings will describe what self-care mechanisms were used by social workers to buffer their stress and to become replenished.

Chapter II will present a review of the broad topical literature, i.e. complexity of caring for HIV-infected patients, the range of job-related stressors, and how this impacts AIDS social workers.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

This following chapter will summarize the professional literature on stress, burnout, and HIV/AIDS social work. I will also address the unique aspects of HIV/AIDS work and its impact on health care providers, and more specifically, social workers. Additionally, factors such as disease progression, occupational stress, stigma and discrimination, and the cumulative grief response to the multitude of losses of patients, and possibly friends, to HIV/AIDS, will be documented.

The role of the organization in response to work-related stress and burnout in HIV/AIDS will also be discussed. The literature review also describes both formal and informal social support systems and how they positively or negatively impact staff.

The AIDS Pandemic

Characteristics and Early Responses

Exposure to Human Immunodeficiency Virus (HIV) may result in a disease characterized by a gradual deterioration of immune function and has been ruled as the causative agent for Acquired Immunodeficiency Syndrome (AIDS) (National Institute of Health, 2003). First identified in 1983, HIV/AIDS has advanced rapidly. Statistics from 2001 indicate, "There are an estimated 800,000 to 900,000 people living with HIV in the United States with approximately 40,000 new infections occurring every year" (Center for Disease Control and Prevention, 2003, p. 1). AIDS is a worldwide pandemic that does not discriminate by gender, religion, ethnicity, or socioeconomic status, it has, however, disproportionately affected minority groups in the United States (Center for Disease Control and Prevention, 2003).

Even though women have increasing rates of HIV infection, men still account for 70 percent of new infections. HIV/AIDS, however, is the fifth leading cause of death in women, aged 25 to 44, in the United States; among African-American women, HIV/AIDS is the third leading cause of death (Center for Disease Control and Prevention, 2003). Furthermore, with regard to race, more than half of the newly infected are African-Americans. Hispanics are also disproportionately affected (National Center for Health Statistics, 2002).

During 2001, nearly 468,000 AIDS-related deaths were reported in the United States (Center for Disease Control and Prevention, 2003). While staggering, these figures pale in comparison to the year 2000 worldwide estimates of 36.1 million people living with HIV/AIDS and 21.8 million HIV/AIDS-related deaths (National Institute of Health, 2003). As these numbers continue to grow, the need for well-trained health care providers will become increasingly urgent.

While the sheer breadth of the disease is overwhelming, the problem is intensified further by the fact that the populations most affected by the AIDS pandemic are also among the most vulnerable groups in today's society, i.e., younger populations, women, and people of color. These groups have lacked a financial and political power base.

To make matters worse, as society has become more aware of the spread and mode of disease transmission, discrimination and social ostracism which socially stigmatized populations such as gay and bisexual men, intravenous drug users, people of color, and commercial sex workers experienced prior to the AIDS epidemic has been exacerbated (Ross, 1993). These populations commonly include indigent individuals who are poverty-stricken and living in poor social conditions, and who lack access to affordable and adequate health care, drug treatment programs, and other educational/prevention resources.

These social problems can further intensify the effects of HIV illness on the patient (Honey, 1988; Snider, Salinas & Kelly, 1989), and ultimately can cause additional stressors for health care providers, such as AIDS social workers who work with them. Stigma, social ostracism, and discrimination have been reported by health care workers caring for people with AIDS (Scherr, 1995). Stressors related to how HIV progresses and the lack of cure for this disease only increase the impact on those providing care.

The Changing Role of Social Workers in AIDS

Strug, Grube and Beckerman (2002) "conceptualized the history of the disease (AIDS) in three waves" (p.2). In their article, they discuss these waves in terms of the changing roles of social workers caring for this population. The initial phase, in the early 1980s when little was known about the origin of the disease or its routes of transmission, social workers typically worked with gay, white men who often died within a two-year time span after their initial diagnosis. Social workers spent much of their time dealing with the stigma, discrimination, and issues of death and dying.

The next phase in the AIDS epidemic, from the mid- 1980s to early 1990s was marked by the identification of the retrovirus HIV and the advent of Zidovudine (AZT) drug treatment. The face of AIDS also was changing from gay, white men to intravenous drug users, heterosexual women and their children, and people of color. Social work roles included working with people experiencing a multitude of psychosocial issues such as substance abuse and homelessness. Mandatory HIV testing and partner notification raised new practice dilemmas and ethical decision-making issues for social workers.

The most recent era in HIV/AIDS, the late 1990s to the present, has seen significant pharmacological and medical advancements. Protease Inhibitors such as Saquinavir, used in combination with other drugs, has changed AIDS from a terminal illness to a chronic disease. Such highly active antiretroviral therapy, known as HAART, has made dramatic changes in decreasing the AIDS mortality rate, while improving the quality of life of those infected. Although these medical advances have radically improved treatment options for many, there are still those with HIV infection who cannot benefit from treatment due to a lack of medical response or financial accessibility (Strug, Grube and Beckerman, 2002).

As those who are infected live longer, social workers now spend more time on issues related to chronic care management. Their work becomes more about living with AIDS, than dying with AIDS. Counseling related to reproductive choices, applying for disability, and safer sex is a result of patients surviving longer, dealing with new relationships, and other life transitions. Although both treatment advances have significantly improved quality of life and life expectancy, the number of new infections continues to grow. Therefore, the role of social work also is expanding preventing new infections, as well as working with the increasing numbers of infected patients (those newly infected to those in the terminal stage of the disease).

Disease Progression

After initial exposure to the virus, HIV-infected individuals develop flu-like symptoms (National Institute of Health, 2003), which cease relatively quickly as the body increases its immune response and attempts to fight back with killer T-cells and B-cell-produced antibodies. An infected person may remain asymptomatic (free of HIV-related symptoms) for 10 to 12 years, despite continuous replication of HIV in the lymphoid organs, seeded during the initial phase of infection. As the disease progresses, infections and complications, such as Pneumocystic Carinii Pneumonia, confirm a full-blown AIDS diagnosis.

Once AIDS is diagnosed, it is often a very painful, disfiguring disease, marked by multiple hospitalizations and a complex course of treatment. Because the immune system is compromised so severely, the infected person may experience multi-system failures. Up to 50 percent of HIV-infected people experience neurological manifestations, including peripheral neuropathy, which inhibits an individual's ability to walk. Neuropsychiatric conditions, such as HIV encephalopathy and multi-infarct dementia, may also complicate the clinical progression of the disease further, potentially rendering the person mentally incapacitated. Wasting syndrome (i.e., severe weight loss), cancer (Kaposi's sarcoma), pneumonia (Pneumocystis Carinii Pneumonia), and cytomeglia virus in the retina (which frequently causes blindness) are all associated with advancement of the disease (National Institute of Health, 2003). In addition, people with AIDS may experience less serious physical symptoms, such as night sweats, fevers, chronic diarrhea, and lymphadenopathy (lymph nodes that are abnormal either in size, consistency, or number (Ferrer, 1998).

Several psychological and behavioral conditions are associated with AIDS as well, including anxiety, depression, exacerbation of pre-morbid psychiatric disease, and suicidal ideation. Victims of AIDS have also been known to exhibit feelings of hopelessness, anger, apathy, irritability, depression, low self-esteem, and guilt (National Institute of Health, 2003; Rodgers, 1995).

Given the physical and psychological ramifications of this disease, it is understandable that working with AIDS patients can create multiple stressors for caretakers. Observing patients decline, waste away, or become mentally incapacitated as a result of the spectrum of HIV-related illnesses takes its toll on those caring for them. Social workers caring for individuals with AIDS are often there from the initial diagnosis to the end-stage of the disease.

As a result of recent medical and psycho-pharmacological advances, HIV/AIDS has increasingly become a chronic, progressive illness. However, even without a fatal prognosis, AIDS nonetheless places a profound emotional burden on patients living with the disease and on their care providers. In the following section, I will address the issues of job-related stress and its impact on social workers.

Job-Related Stress

Much debate has centered on the many definitions of stress. Although it is a highly discussed topic in today's society, stress is rarely defined in the same way by different people or across different disciplines. Even after years of inquiry, it continues to be redefined in the literature (Selye, 1993).

Selye defines the most simple form of stress as a "nonspecific result of any demand on the body--be the effect mental or somatic" (p. 7). From a more focused, social science perspective, Evans and Cohen (1987) view stress as a "relational concept signifying an imbalance between environmental opportunities and individuals' goals and response capabilities to cope with that imbalance" (p. 573).

Irrespective of how it is defined, stress is often the result of an individual's work environment and the job demands and responsibilities of his/her position (Koeske & Koeske, 1993; Lambert, Lambert, & Yamese, 2003). Siu and Cooper (1998) define job-related stress as "the mind-body arousal resulting from physical and/or psychological demands associated with a job" (p. 55). They continue to explain that high levels of job stress may lead to employee distress if the job is too intense or the stress too frequent. Jamal (1999) notes, "In this conceptualization of stress, it is the chronic nature of job stress, which implies that job stress arises when the individual does not fully recover between workdays, causing lasting psychological strain" (p. 153). Such unrelenting and unrelieved stress has been recognized as an important factor contributing to deterioration of employees' personal health and well-being. In addition, stress may result in numerous organizational problems, such as job dissatisfaction, burnout, high absenteeism, low organizational commitment, and marginal job performance.

In 1979, Karasek developed an integrative model of job stress within the cognitive paradigm (Tyler & Cushway, 1998), which he termed "The Job Strain Model". In this model, he postulates that stress gives rise to strain (worker dissatisfaction and depression, ultimately leading to ill-health) only when job demands are high, and discretion (amount of control over their work environment and their ability to choose tasks and allocate time) for meeting these demands is low. More specifically, as quoted in Tyler & Cushway, Karasek's theory states:

> These two aspects of the job situation (job demands and discretion) represent, respectively, the instigators of action (work load demands, conflicts, or other stressors which place the individual in a motivated or energized state of 'stress') and the constraints on the alternative resulting actions. The individual's job decision latitude is the constraint which modulates the release or transformation of 'stress' (potential energy) into the energy of action. Thus, this is a stress-management model of strain which is environmentally-based. If no action can be taken, or if the individual must forego other desires because of low decision latitude, the unreleased energy manifest itself internally as mental strain (p. 287).

Although job-induced stress does not always have a negative impact, excessive or chronic stress ultimately can produce severe negative outcomes. As early as 1956, Selye demonstrated a physiologic breakdown occurred in animals exposed to prolonged periods of stress. In chronically or excessively stressed individuals, this physiological breakdown manifests as a wide range of physical, mental, and behavioral disorders. Common psychological disorders include depression, job burnout, anger, and sleep disturbances (Siu & Cooper, 1998). Signs of physical distress include backaches, headaches, ulcer disease, and cardiovascular problems. Finally, common symptoms of behavioral stress include substance abuse, violence, and accident proneness.

Health care workers caring for patients with HIV/AIDS have been shown to have high stress levels which can ultimately lead to burnout (Gordin, 1987; Ross, 1993). Understanding how stress impacts these workers and what, if anything can be done to alleviate it in order to retain experienced, dedicated staff is an ongoing challenge in AIDS organizations. The amount of stress experienced may be exacerbated by the work setting and the needs of different patient populations, such as the terminally ill. This is especially true for hospital social workers, who have been on the front-lines, caring for patients with HIV/AIDS, since the beginning of the epidemic.

Hospital Social Work

Considerable attention is paid in the professional literature to the need for health care workers to maintain their emotional resilience, while effectively helping patients cope with the multitude of stressors related to having a chronic or terminal illness. Tyler and Cushway (1998) recognize the disproportionately stressful nature of such work:

> The job of caring for vulnerable people, together with associated uncertainties about the effectiveness of treatment and the need to hide their natural self-doubt about their own competence, makes health care professionals a high-risk group (p. 99).

Yet, the need to understand the stressors experienced by health care workers, as well as understanding how they cope and replenish themselves, is essential in providing optimal patient care. This is especially relevant to hospital-based social workers, who are often responsible for providing emotional, social, and psychological care to patients with life-threatening illnesses.

Sze and Ivker (1986) further elaborate this need in a study of stress in social workers. They found social workers in hospital settings experience more frequent stress than social workers in other settings. The authors speculate that job-related stressors, the changing role of hospital social workers, and increasing organizational pressures account for this increased level of stress. Koeske and Koeske (1989) warn that, as a result of this heightened level of stress, hospital social workers are at serious risk for emotional exhaustion.

Alternatively, a recent article by Pockett (2003) portrays hospital social work as a "challenging and fertile environment for social work practice" (p. 1). Recognizing the critical need for social workers to survive and thrive in hospital-care settings, there are two important reasons to study the continuing role of social workers in hospitals:

> Hospitals have been traditional employers of large number of social workers since the profession began at the turn of the 20th Century. Secondly, there has always been a relationship of significance between trends which have occurred in hospital social work practice and events in the rest of the field (p.2).

For hospital social work administrators like Pockett, understanding the reasons why hospital-based social workers stay, rather than finding jobs in other less stressful settings, is essential to maintaining qualified, resilient staff. Through her study, using qualitative interviews with Australian, hospital-based social workers, Pockett come to understand this phenomenon better, findings that "self-actualisation" is a key to explaining why people stay. Accordingly, she found hospital social workers who were self-actualised in their work tended to be more open to new experiences, more willing to change, and more able to tolerate ambiguity in the workplace than their peers who had low tolerance or low self-actualisation and who left the hospital setting. Pockett attributed self-actualisation to personal qualities of "hardiness" which could be supported within the work setting. Nonetheless, even in her more positively oriented research, hospital-based social workers were found to be at risk for burnout and for abandoning this stressful setting.

In addition to setting-related stressors, social workers caring for chronically- and terminally-ill patients have been found to have higher stress levels than their hospital-based colleagues (Siefert, Jayaratne, & Chess, 1991). Numerous other studies have focused on the problems of stress and burnout among these professional caregivers, including social workers (Gordin, 1987; Oktay, 1992; Ross, 1993). All such employees face the inevitably forceful and negative outcome of their work — the death of the patient (Ray, Nichols, & Perritt, 1987). While unable to reverse the outcome, social workers can help ease, and make more meaningful, the dying process (Evans, Esbenson, & Jaffe, 1981). Ray and colleagues (1987) suggest these workers face high levels of uncertainty, "the *only* certainty being that their patient will die eventually" (p.5).

Social workers working with the terminally ill necessarily spend considerable time with the patient and their family members. In doing so, they may find themselves in the midst of the family's interpersonal conflicts, unresolved feelings, or other psychosocial problems. As a result, they may feel uncertain about how much help they can provide for patients and families while dealing with end-of-life issues. Coupled with heavy caseloads, numerous deaths, and little time for grieving, it is understandable that social workers are at heightened risk for physiological and psychological problems related to stress (Vachon, 1979).

In addition to the literature related to stress in hospital workers providing care to the chronically and terminally ill, a body of literature focused more specifically on the stress experienced by those working with AIDS patients (Oktay, 1992), a disease process which exacerbated an already stressful environment. Paton (1992) asserts "in spite of, or because of, the vision and passion of AIDS caregivers, overwhelming stress is a major by-product for formal and informal caregivers" (p. 1). In the next section, I will address these issues.

AIDS Social Workers

The increased stress levels associated with hospital social work, coupled with a patient population that is both chronically and terminally ill, puts AIDS social workers at heightened risk for stress and burnout (Egan, 1993). High levels of stress in hospital social workers prior to the AIDS pandemic were primarily the result of working with patients in critical care, oncology, and emergency services (Paradis, 1987). Although death was not uncommon in these settings, the social workers in AIDS reported much different stress-generating experiences than their counterparts (Scherr, 1995).

In a 1993 study, Ross identified a multitude of stressors in the social service field that are not unique to AIDS work, including poorly defined work teams, increased time pressures, role conflict and ambiguity, inability to influence policy, lack of social support, limited status, and poor promotional opportunities. Ross states these stressors are exacerbated for individuals working with AIDS patients and suggests additional stressors such as multiple losses, fear, discrimination, emotionally draining work, and complex psychological needs with limited resources also take a toll on AIDS service providers.

Other stressors have been identified for AIDS social workers. Cushman, Evans, and Namerow (1995) identified the fear of contagion, discomfort with the social dimensions of AIDS, and professional inadequacy as stressful aspects of clinical AIDS work.

In the early days of the pandemic, professional ignorance about AIDS was observed in a survey conducted by Peterson (1991), who found less than half of the survey questions concerning knowledge about AIDS were answered correctly by the social work responders. This lack of knowledge could potentially heighten anxiety and stress reactions; one can only hope this knowledge gap has been filled among AIDS social workers over the last decade.

Other stressors specific to this work include: the social stigma and discrimination associated with AIDS; the youth of many patients; the neurological aspects of AIDS; the uncertainty of who will respond favorably to new treatments; death and dying; the specter of multiple members of a family being infected; over-identification with patients; dealing with patients' families; and a sense of therapeutic impotence in the face of death (van Rooijen, 1993). A study of AIDS emotional support volunteers conducted by Guinan, McCallum, Painter, Dykes, & Gold (1991) also identified emotional overload, client problems, and lack of support and training as key stressors among AIDS caregivers.

The work of Rowe, Plum, and Crossman (1988) acknowledges the higher risk of burnout in HIV-related work and several reasons for this increased stress, most notably the progression of HIV disease and of disease characteristics. The sense of loss and helplessness common among AIDS social workers was reported by Wiener, (1986), while Pomerance & Shields, (1989) found that AIDS health care workers reported feeling emotionally drained, citing increasing caseloads, personal safety concerns, and caring for young persons with a terminal illness as reasons for their exhaustion.

A 1995 study by Cushman, Evans, and Namerow identified specific stressors in the work environments of HIV/AIDS social workers, health educators, and counselors in five urban medical centers. The most commonly cited stressors are specific to AIDS caregivers, including issues related to death and dying, the severe physical illness experienced by AIDS patients, the inability to find a cure or solution to AIDS, giving HIV test results, and the unpredictability of disease progression. Stressors associated with organizational issues were mentioned with nearly the same frequency, and included heavy caseloads, understaffing, working in a bureaucratic environment, inadequate job benefits, low salaries, threats to funding, and lack of support groups.

The lack of workplace support groups, as well as limited support from caregivers' family and friends were studied further by Gordon and colleagues (1993). Nurses working with AIDS patients were found to receive very little support from family and friends. The authors suggested this may reflect society's stigmatization and avoidance of people associated with AIDS. This lack of support serves as an additional stressor and may ultimately cause loss of confidence and self-esteem among workers who feel judged according to their area of work or their HIV status. The fear of an occupational exposure to HIV disease also creates an additional emotional burden.

Social workers have always worked with indigent populations who lack resources and access to services or treatments. Coupled with the nature of HIV/AIDS and fear of occupational exposure, however, creates additional distress for AIDS social workers. Compared to their nursing/physician counterparts, health care professionals such as social workers were found to be at low risk for occupational exposure to HIV (Center for Disease Control and Prevention, 1989). Transmission through needle stick or blood splashes were only reported by health care workers responsible for direct physical care of the patient. Although the risk of occupational exposure to the HIV virus was extremely low for social workers, there were other high job-related risks. These will be addressed in the next section.

Occupational Stress

Fear of Exposure

The emotional toll on health care providers has been present since the beginning of the AIDS pandemic, but has evolved as more information became available. Prior to the discovery of the virus causing AIDS, and with limited knowledge of how the disease was being transmitted, health care workers provided "hands-on" care to this patient population. Such care was, for the most part, provided willingly, yet not always without a personal struggle. Fear of contagion and occupational exposure, fear of the unknown, fear of contracting a fatal disease, and apprehension about personal and family safety were realistic concerns which confronted these professionals daily. Fears caused some health care providers to discriminate against patients by withholding or refusing treatment or by taking unnecessary medical and isolation precautions, thus creating physical and psychological barriers to quality patient care.

Early attempts to document AIDS stressors were described anecdotally by health care workers, primarily physicians and nurses. Later, research used stress scales and burnout inventories to document the high risk of stress and burnout in AIDS work (Bennett, Michie, & Kippix, 1991). Stein, Wade, & Smith (1991) chronicled the experience of nurses caring for AIDS patients:

> Special stressors, such as the intensity of emotional and physical needs of this patient population, along with the ongoing clinical and ethical dilemmas, make caring for patients with AIDS an exhausting job for nurses (p 30).

Several early studies of stress and health care workers focused on the fear of occupational exposure to HIV disease (Itzhaky & Atzman, 1999; Ross, 1993). Once more was known about routes of transmission, these fears were replaced with concern for one's emotional well-being when caring for people with AIDS. As occupational exposure became less of a concern, health care workers began to emphasize other emotional hazards of AIDS work (Bennett, Michie, & Kippax, 1991; Gordin, 1987); such as frequent staff turnover, grief overload, and burnout from chronic, excessive stress (Schoen, 1992). The reasons for continuously high stress levels in AIDS social workers included the devastating physical and mental deterioration associated with HIV illness.

Given the infectious nature of HIV disease, fear of contagion exists even for AIDS social workers who are at very low risk for an occupational exposure (Ross, 1993). Despite the very low transmission rate amongst health care workers, there was irrational fear of contracting this devastating, incurable disease. Many health care providers experienced a tremendous emotional toll until more information became available about the disease and its transmission.

Several studies affirmed health care providers' fear of occupational exposure, feelings of professional impotence in treating people with a fatal disease, and a lack of comfort with behaviors that put patients at risk for contracting this illness, such as homosexuality and intravenous drug use (Ross, 1993; Ryan, 1991; Wiener & Siegel, 1990). Watching many patients die can create feelings of loss and hopelessness in AIDS caregivers (Ross, 1993), especially when the number of losses is so extreme. Moreover, it is not uncommon for multiple family members, including spouses and children, to be infected through unprotected sex and maternal transmission (Ross, 1993). Thus, grieving several members of the same family who have died from this disease becomes an additional stressor. Cumulative loss and grief responses often plague health care providers namely, AIDS social workers, who are working most closely with patients' emotional and psychological needs.

Ethical and legal problems encountered by AIDS patients, such as rational suicide and refusal to insure, made it even more difficult to provide care to this population. Even as more was learned about how HIV is transmitted, there was less fear, but the stigma and discrimination often continued.

According to Chateauvert (1993), "AIDS engenders a host of social, financial, and ethical problems along with the physical ones" (p. 54). Isolation, stigma, and blatant discrimination are common concerns for people who are HIV-infected, as well as for their health care workers. Fear of the unknown and fear of contagion are the underlying cause of many of these problems.

As health care workers became better informed, there was less fear of an occupational exposure. Incidents of health care workers refusing to care for patients or using unnecessary protection declined. At the same time, universal precautions were put into effect in all health care facilities. Regardless of risk all patients were treated as if they were potentially infected, which provided a secondary benefit of additional protection against other blood-borne pathogens, such as Hepatitis B and C.

Unfortunately however, at this same time, there was an emerging airborne disease converging in the HIV-infected population, Pulmonary Tuberculosis (TB), which had been on the decline for many decades. This created yet another round of fear of contagion, stigma, and discrimination for the same patients. Fear of exposure and contagion was also experienced by those caring for them, namely, health care workers (Gordin, 1987).

Pulmonary Tuberculosis

In the early 1990s, AIDS was being associated closely with an airborne contagious disease, mycobacterium tuberculosis (TB), better known as pulmonary tuberculosis. Incidence of TB increased sharply in immunosuppressed HIV-positive patients, creating a resurgence of fear and stigma for health care workers (Wade, Stein, & Beckerman, 1995).

Social workers now put themselves at risk for an occupational exposure just by providing face-to-face care for patients. Many HIV-infected patients had undiagnosed pulmonary tuberculosis, creating the risk of exposure (via droplets in the air) by anyone in contact with them. This was especially trying for social workers working in enclosed spaces, such as a hospital rooms. Multi-drug resistant strains of tuberculosis, which contributed to hundreds of deaths in immunocompromised HIV-infected patients, were also responsible for death or illness in many health care workers (Wade, Stein, & Beckerman, 1995). Issues concerning the fear of tuberculosis contagion emerged with increasing frequency in HIV patients diagnosed with TB. In addition, health care workers feared that they were at risk for contracting TB from patients who had not yet been diagnosed, but were infectious. Moreover, patients who were unable to or refused to follow the prescribed treatment course for TB put those around them at greater risk of developing untreatable strains of TB that were sometimes fatal. This situation further intensified the already high levels of stress experienced in AIDS work. Fear for one's personal safety and for that of their family again created stigma and discrimination against HIV-infected individuals (Wade, Stein, & Beckerman).

As with AIDS, TB has disproportionately affected the minority population. According to the Center for Disease Control and Prevention (2003), "TB was once the leading cause of death in the United States" (p.1). After years of declining rates, TB was once again on the rise. Then in 2000, more than 16,000 cases were reported (Center for Disease Control and Prevention). Inadequate housing and health care, limited availability of drug treatment programs, and lack of education and resources exacerbated the spread of both HIV and TB (Wade, Stein, & Beckerman, 1995). The need for social work intervention in such a situation was often as great as the need for medical treatment.

Health care workers' fear of being exposed to these diseases was quelled by good infection control policies and procedures and creative programming to reach and treat those infected. Yet, a new concern was being voiced--how to deal with the multitude of losses associated with this work. Patients with HIV/AIDS often faced a terminal illness having no cure. Dealing with death and dying and bereavement issues added yet another dimension to the stress experienced by hospital-based social workers.

Grief Response

Because of the repetitive losses experienced by AIDS social workers, many report feelings of "grief overload" (Scherr, 1995). This term has been broadly understood to mean facing frequent losses without fully grieving the deaths. Social workers have reported just such an overload, having inadequate opportunity to grieve a loss before they were assigned a new patient who also would eventually die (Schoen, 1992). As much as a decade ago, cumulative grief responses were beginning to be described by AIDS social workers (Schoen). AIDS teams, managers, and health care organizations were unprepared for this response among their staff and did not know how to mobilize the resources necessary to deal with this overwhelming grief.

On this point, Ryan (1991) states: "Few agencies have adapted policies to manage the high stress and grief overload associated with providing care to people with AIDS, thus contributing to the burnout of social workers in those settings" (p. 9). Ryan continues, asserting that, to maximize patient care and program effectiveness organizations must develop strategies to manage high stress levels and grief overload associated with providing care to people with AIDS.

Another study (Doka, 1989) introduced the concept of "disenfranchised grief", to assist the understanding of a loss that is not socially sanctioned. It recognizes societies' specific sets of norms as to who grieves, for how long, where, when, and how. Doka contends the disenfranchised griever suffers a loss, but has little or no opportunity to mourn publicly. Thus, due to society's preference for kin-based relationships, it is easy to understand why those who experience AIDS-related bereavement, including health care professionals, will encounter difficulties in the grieving process; because their grief is disenfranchised (Bennett, 1995).

Despite the difficulties of unresolved and relentless grieving, working with dying patients is not experienced entirely as a stressor in AIDS work. On the contrary, Oktay (1992) noted AIDS social workers reported helping patients who are dying and "witnessing the courage of patients and their families" (p. 437) added to their feelings of personal accomplishment. Even though these workers often reported extremely high levels of emotional exhaustion and depersonalization, they also reported higher levels of personal satisfaction than other hospital social workers.

Thus, working with dying patients does not fully explain why AIDS social workers experienced higher levels of stress or burnout, nor does their feeling overwhelmed stem from solely the sheer numbers of patients dying. Other factors are also involved.

As more effective drug therapies became available for those infected with HIV, characterization of the disease slowly began to shift from that of a terminal disease to that of a chronic illness (Strug, Grube, & Beckerman, 2002). Although a terminal phase remains for patients diagnosed with end-stage AIDS, patients are staying healthier and living longer. Thus, the death and dying work of both patients and caregivers may also shift as patients live longer and more productive lives. This change constantly creates new challenges for providers, but may also allow for new opportunities in job satisfaction for AIDS providers as well.

Organizational Stressors

There are a host of organizational variables which play a role in exacerbating stress or in mediating its effects on AIDS social workers. Pressures related to working in a bureaucratic organization, which increases job-related stress, have been well researched (Parry, 1989; Sotile & Sotile, 2002). Rigid work environment, lack of worker autonomy and flexibility, heavy caseloads, limited resources, and shortened timeframes for complex discharge planning can further exacerbate the already high stress level for AIDS social workers. Retaining and replenishing social workers who work within these bureaucratic organizations becomes an even greater challenge (Oktay, 1992. This is especially true when formal and informal support structures are limited or non-existent within the work environment.

In New York State some of the foregoing organizational stressors were countered by the emergence of AIDS Designated Centers (ADCS). These centers arose from the political, financial, and social pressures which created a need for different methods of caring for people with AIDS, both in the hospital and community. Enhanced reimbursement rates from state and federal monies enabled hospitals to hire necessary staff and create an infrastructure to provide quality care, while remaining fiscally viable during the onslaught of this pandemic.

AIDS Designated Centers

Under the auspices of the Department of Health, New York hospitals were able to apply for an AIDS-designated status. Once designated, they were responsible for providing comprehensive, coordinated care to patients who were HIV symptomatic or had full-blown AIDS. Hospitals were then able to offset some of the costs of caring for AIDS patients through an enhanced in- and out- patient reimbursement system funded by state monies.

At first, many hospitals refused to apply for ADC status for fear of being identified in the public mind as an "AIDS Hospital". As it became clear patients with AIDS were being treated in every hospital anyway, and that care for this population required labor-intensive, complex, and expensive treatment, more hospitals applied for designation. The number of ADCs rose from two or three in the late 1980s to seventeen in the early 1990s. Case management was implemented in each AIDS Center, and developed as "a client-level strategy for promoting the coordination of human services, opportunities and benefits" (Moxley, 1989, p. 11). This model was implemented and audited by the AIDS Institute and, in turn, monitored by the New York Department of Health. Each institution could define the model they used, but were required to meet general guidelines for HIV-coordinated care (whether the patient was in the hospital or in the community) and to document these services.

Accordingly, the health care team for each case was responsible for organizing, coordinating, and sustaining a network of formal and informal supports and activities designed to optimize the functioning and well-being of patients having a multitude of health and social problems. The case manager functions as the coordinator of these team activities. In many institutions, the social worker is assigned as the case manager.

With the case manager title came various additional roles and functions beyond the social work role. These included facilitator, coordinator, communicator of the team activities, community and resource advocate, and gatekeeper of resources. The gatekeeper function ensured services were appropriate to the rapidly changing needs of the HIV-infected patient. The social worker was also an integral member of the medical treatment team and frequently developed strong bonds with the patients, working with them over the course of their illnesses.

Case management programs varied from organization to organization. One aspect that differed between programs was the implementation of a continuity of care model. In this model, patients are enrolled in the case management program and inpatient and outpatient care are coordinated. However, they are not necessarily managed by the same person. For example, an inpatient social worker might follow the patient throughout a hospitalization, and then transfer them to an outpatient social worker for follow-up in the community.

Most programs tried to designate a team approach. The team usually consisted of a physician, nurse, and social worker who provided case management through continuity of care model. Whether the person was in the hospital or at home, the same core team provided their care.

There were pros and cons to each of these models. Social workers using a continuity model followed a patient anywhere in the hospital and were available to them throughout the course of their illness. Thus, the social worker might experience increased stress from this long-term, intensified relationship. Yet social workers transferring a patient to another worker during an inpatient stay might feel they were abandoning their patient, especially during the terminal phase of their illness. On the organizational side, the pressure for expedited, complex discharges and the limited availability of community resources might actually increase the worker's stress. In either model, the AIDS social worker is at the center of the treatment team and, consequently, at greatest risk of occupational stress.

Health Care System Stressors

AIDS social workers provide intensive work such as counseling, crisis intervention, and referrals to myriad social service agencies. Advocating for services, negotiating the labyrinth of human service organizations, and coordinating the ongoing care of AIDS patients can be exhausting and draining.

In addition, job related stressors, the changing role of social workers in hospital settings, and increasing organizational pressures have for more than a decade accounted for additional high levels of stress in social workers (Sze & Ivker, 1986). However, much of the literature on AIDS social work stress predates the serious financial problems more recently experienced by hospitals throughout the United States as a result of Diagnostic Related Groups (DRG, a system of financial reimbursement), managed care, and a national health care crisis. The stress experienced by hospital social workers certainly may have been heightened by these changes. It is therefore all the more important that health care organizations look for ways to reduce high stress levels and to maintain replenished staff. First, however, they must understand the specific factors creating stress in these workers, especially in health care settings.

There is a need to identify the stressors having the greatest impact on social workers. In order to change things, institutions must explore coping strategies or interventions to reduce stress and maintain existing staff.

Clearly, the stress inherent in working in HIV/AIDS has been widely documented. Studies illustrate the multitude of stressors and potential for burnout for health care professionals (Mantall, Shulman, Belmont, & Spivak, 1989; Oktay, 1992; Ryan 1991). Unfortunately however, there remains a paucity of information on the formal and informal support structures which buffer these stressors and prevent staff burnout. Even fewer studies have examined how stress can be reduced by social service providers who are in high demand in working with AIDS patients (Cushman, Evans, & Namerow, 1993).

The present study is both timely and responsive to caregivers and organizations caring for people with AIDS. It is the next logical step in understanding the support structures needed to maintain existing staff, while preventing burnout in social service providers. Although the existing literature does show some AIDS caregivers get substantial job satisfaction from their work, the negative effects leading to stress and burnout are still present. Burnout can cause a serious threat to staff and the organization through a loss of productivity, poor morale, and high cost of staff turnover (Ross, 1993).

> If providers are not able to replenish their depleted energy on a regular basis, they will be unable to adapt to the stress and become exhausted. This exhaustion may then result in burnout (Ray, Nichols & Perritt, 1987, p. 5).

Burnout

Characterization and History

The use of the term "burnout" began to appear in the literature in the 1970s, especially among professionals working in the human services. Freudenberger is universally credited with coining the term in 1974 (Ursprung, 1986, p.190). A clinical psychologist, Freudenberger was familiar with the stress responses exhibited by staff members in *alternative* institutions such as free clinics and halfway houses. He used the term to describe an "individual condition of physical and emotional exhaustion resulting from excessive demands on energy, strength, and resources" (Offerman, 1985, p.419).

Edelwich (1980) defined burnout as a "progressive loss of idealism, energy, and purpose experienced by people in the helping professions as a result of their working conditions" (p. 6). Others have concluded burnout is a state of emotional exhaustion resulting from working with people in emotionally draining situations (Johnson & Stone, 1987).

Christina Maslach, a social psychologist, studied emotions in the workplace in the early 1970s, and later, described burnout as "a syndrome of emotional exhaustion, depersonalization and reduced personal accomplishment that can occur among individuals who do people work of some kind" (Maslach & Jackson, 1981, p. 99). Thus, burnout is an individual, negative, affective experience occurring as a result of chronic work stress (Offerman, 1985). Continuing in this vein, Maslach and Lieter (2001) recently defined burnout as "an individual stress experience embedded in a context of complex social relationships, and it involves the person's conception of both self and others" (p.416).

Manifestations of burnout include depression, irritability, anxiety, lowered self-esteem, fatigue, helplessness, insomnia, headache and gastrointestinal problems (Jackson & Maslach, 1982). The most critical aspect of burnout in the health care professions "is its link to deterioration in the quality of care or services provided to clients or patients" (Leiter & Maslach, 2001, p.416).

Many researchers studying the dynamics of burnout focus on stages which characterize the degree or extent of burnout being experienced. For example, Edelwich (1980) describes four stages, from enthusiasm to apathy, as follows:

1. Enthusiasm: over-identification with clients and excessive, inefficient expenditure of one's own energy;
2. Stagnation: a sense of merely conducting the work;

3. Frustration: with the type of work; and

4. Apathy: used as a defense against the frustration

According to Beemsterboer & Baum (1984) Maslach discusses fatigue as a major by-product of stress. In this three stage model, she emphasizes various kinds of fatigue:

1. Physical fatigue and feeling drained;
2. Psychological fatigue with alienation from client work; and
3. Spiritual fatigue which involves self-doubt (p.102).

Burnout is known to lead to deterioration of both the quantity and quality of work, and has been a factor in low worker morale, increased absenteeism, and job turnover (Ross, 1993). From a managerial perspective, the significance of burnout lies in the fact that it is dysfunctional, not only to employees' well-being, but also to the productivity of the agency (Beemsterboer & Baum, 1984). Burnout has been linked to job dissatisfaction (Maslach & Jackson, 1982), poor job performance (Nowack & Hanson, 1983), and the intention to quit one's job (Maslach & Jackson, 1984).

Burnout also has been correlated to certain factors in job settings, including caseload size, communication networks, greater percentage of time in direct client work, and difficult client problems (Coady, Kent, & Davis, 1990). In addition, work pressure, greater role conflict, low degree of peer support, and lack of promotional opportunity have been correlated to burnout (Offerman, 1985).

Although the conceptualization of the stages of stress may vary, many authors assert chronic emotional drain induces burnout, and should be avoided (Johnson & Stone, 1987). The question is how?

Early work on burnout begun in the 1970s "was exploratory and had the goal of articulating the phenomenon of burnout" (Maslach, Schaufeli, & Leiter, 2001, p. 398). Research was based on experiences of people working in human services and health care and "most of the research was descriptive and qualitative in nature". Several themes emerged from this early work, suggesting "that the burnout phenomenon had some identifiable regularities" including "emotional exhaustion, depersonalization, and a better understanding of job factors that contribute to burnout" (Maslach, Leiter & Schaufeli, p. 399).

Measuring Burnout

Bergman, West, and Lewiston (1979) identified stress- related symptoms that precipitated burnout in social workers caring for cystic fibrosis patients. These four factors were: (1) unpredictable course with a hopeless prognosis (2) long-term contact with patients and families (3) labor-intensive therapy, and (4) poor response of the U.S.health care system to the needs of the chronically ill.

More systematic studies of burnout began in the 1980s. Maslach and Jackson (1981) designed a scale, called the Maslach Burnout Inventory, which could be used to assess burnout in human service professionals. This scale continues to be the most widely used by researchers today. It is a twenty-two item self-inventory, divided into three subscales which Maslach and Jackson (1981) suggest best capture the multi-dimensional experience of burnout. Their three subscales are: (1) emotional exhaustion, (2) depersonalization and (3) lack of personal accomplishment. The first subscale includes nine items measuring feelings of being emotionally overextended and exhausted by one's work. The five-item depersonalization subscale measures an impersonal and uncaring response to one's clients or work. The third subscale assesses feelings of incompetence and lack of success in one's work.

Those scoring high on emotional exhaustion are thought to be unable to give of themselves in their professional work with clients. High depersonalization scores indicate a worker's negative attitudes or cynical feelings about ones' clients. Low personal accomplishment scores indicate a tendency to feel negative about one's work or dissatisfied with one's accomplishment on the job. Maslach and Jackson go on to suggest the pattern of burnout, as indicated by scores on the Maslach Burnout Inventory, may be critical factors indicative of different stages of burnout. They speculate that intervention may be more useful in early rather than later stages of burnout.

In 1990, researchers used the Maslach Burnout Inventory to measure stress levels and symptoms of burnout in social workers working with chronically ill cystic fibrosis patients (Coady, Kent, & Davis, 1990). The authors reported high levels of emotional exhaustion and depersonalization in social workers who had more than thirty hours of direct patient contact per week. The findings of this research also showed certain interventions could increase feelings of personal accomplishment, while lowering feelings of depersonalization. Support from team members and supervisory support were two examples of successful interventions cited.

There are many similarities in the work with cystic fibrosis patients and those with AIDS. First, HIV/AIDS has an unpredictable course and can have a fatal prognosis. Living with HIV has been described by some patients as being on an emotional roller coaster (Strug, Grube, & Beckerman, 2002). The emotional and physical ups and downs from the disease vary from one day to another. Because people with HIV experience a chronic phase with multiple hospitalizations, social workers often maintain long-term contact with them. Also, because there is no cure for AIDS, professionals caring for AIDS patients know many of them will die. Unlike traditional hospice work, in which many patients are older, HIV-infected patients are often young and have been generally healthy before contracting the disease. Like cystic fibrosis patients, people with HIV/AIDS are chronically ill and can die at a young age. In both diseases, helping young people cope with the chronic nature of their progressive illness raises many counter-transference issues, which can intensify the stress caregivers experience i.e., fear of helplessness and over- identification with young patients (Dunkel & Hatfield, 1986).

Despite these parallels to social work with cystic fibrosis patients, there are important differences as well. For example, cystic fibrosis patients do not experience the stigma and discrimination experienced by AIDS patients, and often, by health care workers as well (Gordon, 1993). Further concern about one's personal safety and a lack of accurate information which is a part of AIDS work, but not of cystic fibrosis, can also magnify stress.

Prior to AIDS work, health care practitioners worked with chronically and terminally ill patient populations, and although not exactly the same, the similarities are numerous enough to extrapolate from this research to AIDS work. The burnout literature in these other care fields is extensive and has grown specifically related to AIDS caregivers.

Most research on burnout has focused on human service occupations, with the most frequent reports of burnout among health care workers, teachers, and social workers

(Leiter & Maslach, 2001). Soderfeldt, Soderfeldt, and Warg (1995) found social workers are an occupational group at above–average risk of burnout. Among social workers and nurses, it is not only the profession which creates the risk of burnout, but the setting of the work itself. As Ray, Nichols, & Perritt point out, (Paradis, 1987), "It is generally agreed that the risks for stress and burnout are not equal in all types of health care settings, and that those working with the terminally ill are especially vulnerable" (p. 3).

Thus, Cherniss (1980) describes staff burnout as "a transactional process consisting of job stress, worker strain and defensive coping" (p. 6). The risk of worker burnout, although greater in some settings, is not the same for all staff. Mor and Laliberte (1984), for example, explore the problem of burnout among hospice staff, who are working directly with dying patients, and conclude the worker's age, experience, and length of time employed all affect how staff reacts to this emotionally demanding work.

Ideologically, health care professionals working with the terminally ill inevitably view the dying patient as a visible sign of "failure" (House, 1974). The image of the health care worker as a healer is fundamentally compromised when the patient is dying. Therefore, providing methods for staff replenishment in the face of continuing "failure" is essential in order to work with this patient population. Understanding the types of support necessary to buffer the negative effects of stress and burnout is essential to maintain patient care and effective staff levels.

Burnout in AIDS Social Workers

One of the first studies to document the effect of stress and burnout specific to AIDS social workers was done by Oktay (1992), who used a national sample of hospital social workers. She addressed the factors contributing to stress, including the characteristics of the patient population, the stigma attached to HIV, the numerous deaths, the fears and frustrations related to the work, ethical and legal dilemmas, issues of drugs and sex, the work environment, and counter-transference issues. In her research, both burnout rates and the above factors contributing to burnout were studied. She used questionnaires completed by a convenience sample to ascertain the characteristics of job and setting, the nature of the AIDS work, and support systems which impacted the stress and/or burnout of staff. The Maslach Burnout Inventory was used to measure rates of emotional exhaustion, depersonalization, and feelings of personal accomplishment. Variables found to prevent burnout in this study were: (1) Belonging to a social work department; (2) Belonging to a staff support group; (3) Autonomy in one's work; (4) Not working on an AIDS unit; and (5) Being an older worker.

In general, emotional exhaustion and feelings of depersonalization remained high for AIDS social workers; yet feelings of personal accomplishment were also high. In fact, the study found that, when burnout can be avoided, the work could be experienced as challenging and fulfilling.

There were, however, several limitations to Oktay's study. Because it used a convenience sample of AIDS social workers who were experiencing burnout, some may have self- selected not to respond or had already left the AIDS field. Also, the geographic area of the study focused solely on New York and Massachusetts. Florida and California which experienced high caseloads at the time of the study had also been targeted, but were underrepresented in their responses. In other areas of the country, where caseloads are high, resources are scarce, and HIV knowledge is limited, responses might be different.

Most of the research done on AIDS social workers has determined they are at high risk for increased stress and burnout (Egan, 1993; Oktay, 1992). Egan cautions that, given the growing numbers of patients with HIV/AIDS, the need to maintain experienced social workers is critical. Certain individual or organizational characteristics which impact how stress is experienced have also been identified. Surprisingly, increasing age is related to a lower level of burnout (Bennet, Kelaher, & Ross, 1993). Not surprisingly, however, is the finding that workers who are resilient in the face of high stress cope better with the rigors of AIDS work (Oktay, 1992).

The differences between Oktay's work (1992) and the potential contributions of the present study are as follows:

1. The present study is qualitative and focuses on the positive aspects of AIDS work in order to better understand the process of replenishment;
2. It focuses on the types of individual coping and collective support which helped to buffer stress in AIDS social workers; and
3. The research explores whether there is a continuum between burnout and replenishment and/or what individual and organizational factors influence the workers experience along that continuum.

The next section discusses alternative mechanisms for social support, i.e., personal resources (internal) and organizational support structures (external). In principle each makes a contribution to replenishment. The present study will demonstrate how these factors do so.

Social Support

Extensive research to date has shown that social support reduces stress. As Ell (1985) states,

> Social network ties are presumed to exert both main and buffering salutary effects on health by providing individual's with emotional, informational, and instrumental supports that enhance general well-being, as well as ability to cope with life stressors (p. 338).

Social support can reduce emotional arousal to a tolerable level and mobilize the internal and external resources of staff in maintaining stress mastery (Ell, 1985). Koeske and Koeske (1989) write, "There is good evidence that social support, particularly that supplied by co-workers can buffer the negative impact of workload on burnout" (p. 246). Formal support structures to mediate the effects of stress in AIDS work are not present in all organizations. Informal mechanisms providing social support have been known to emerge simultaneously in the absence of such support (Wade & Simon, 1993).

Ross (1993) views stress adaptation and coping in a four-dimensional model. The **emotional** dimension encompasses increased self awareness and consciousness, including confronting stereotypes and changing one's attitudes. Seminars, consultations, supervision, and experiential learning are used to integrate this dimension.

The **social** dimension has as its base ongoing social support through the use of training, assertiveness training, and morale building. In the **spiritual** dimension, religion, family, and personal values comprise this component. Lastly, the **physical** dimension entails physical fitness through biofeedback, imagery, and other healthy lifestyle behaviors. In this model, each dimension must be addressed, providing a holistic approach to caregiver support.

Support systems and mechanisms can be seen as involving both internal (i.e., psychological) and external (i.e., social-structural) resources. Internal resources involve one's ability to perceive and experience support, as well as to use it to reduce stress. External resources relate to characteristics of the work environment and availability of peer relationships and interactions.

Internal Resources

Kobasa (1982) described the concept of "hardiness" as a characteristic affecting both one's appraisal of stress and one's coping abilities. In other words, the hardy person can experience the same stress level as less hardy colleagues, but through feeling competent and in control, can cope more effectively with it. Egan (1993) defines this intrapersonal capacity for reducing the tension of stress as resilience. Similarly, Ben-Sira (1985) stated that persons confronted by an inordinate amount of stress, but who maintain their coping capabilities, have "internal resilience".

Some authors have reported finding personal strategies to prevent burnout including raising consciousness and increasing the expression of fears and feelings (Furstenburg & Olson, 1990). Training in assertiveness and interpersonal skills has also been found to alleviate stress (Ross, 1993). Yanick (1984) asserts internal resources, personality, and interpersonal relationships affect one's ability to cope. Therefore, Rutter (1987) concluded that intervention strategies can be geared toward worker participation, education, or skill building to maximize intrapersonal resources and empower psychological resources.

Clearly, minimizing the threat of negative stressors, while maximizing the challenge and opportunity of a stressful job, are pivotal in managing the internal resources necessary to reduce stress.

External Resources

External resources include both structural and social factors. For AIDS social workers, external resources are influenced predominately by the culture and structure of the organization in which they work. This environment can either create additional stress for staff or buffer the negative outcome derived from the chronic stress of the job itself. Some external resources for reducing stress are: facilitating formal and informal support structures in the work environment, reducing bureaucratic rigidity, and empowering managers to move toward a democratic management style providing flexibility and autonomy. Yancik (1984) found factors which lead to stress and burnout include administrative problems, time pressures, personnel conflicts, bureaucratic procedures, and work overload.

Social support has been most extensively researched in the hospice literature. These studies tend to concentrate on death and dying, but results indicate social support can buffer stress and prevent burnout (Rodgers, 1995; Yancik, 1989). In one of the first of these studies, (Cobb, 1976) social support was shown to be the most effective resource in buffering stress. According to Rodgers, (1995) social support plays a key role in how an individual adjusts to both psychological and physical distress. In adjusting to high stress levels, Rodgers (1995) found an association between high social support and positive outcomes. Rodgers studied the effect of social support, adjustment, and depression among persons with AIDS. The sample of forty-seven men diagnosed with AIDS answered a self-assessment instrument that measured levels of social support and adjustment to their diagnosis. What she found was "individuals who perceived that they had an increase in social support and individuals who had stable high support reported that they were adjusting better than individuals who perceived they had a reduction in their social support" (p.45). Kobasa, Moddi and Kahn (1992) discuss personal hardiness as an interpersonal coping mechanism. Branner and Albrego (1987) also cite personal resources as important factors for coping with interpersonal stress.

Informal Supports

"Survival bonding" is an AIDS social support phenomenon documented by Wade and Simon (1993). It describes the unplanned, intense interpersonal relationships observed among five pairs of AIDS hospital health workers. Lack of formal support structure, coupled with the overwhelming levels of stress, created an environment which these support relationships blossomed as a buffer to stress and burnout. Using a combination of quantitative and qualitative interviews, the authors reported several themes which emerged in these spontaneously occurring relationships. In the absence of a staff support group or peer support program, pairs of AIDS health care workers formed informal partnerships in response to the stresses of their work. Moreover, the study revealed members of each partnership, in their own way, shared responsibilities and demonstrated mutual respect for and dependence on the other.

In the quantitative aspect of this study, the AIDS social workers reported a multitude of stressors, including large caseloads, client-related stressors, and death and dying issues, particularly watching patients decline both physically and mentally. The research findings indicated, however, that in these mutually dependent peer relationships each pair established a forum for ventilation, stress reduction, decision-making, and bereavement. This informal mechanism of social support reportedly helped practitioners reduce stress and maintain emotional availability to their patients.

In contrast, Schneider (1982) reported on an "intimacy paradox" which can occur in a crisis setting. He used hospice staff as an example of what he terms "easy bonding". In such crisis-type environments, staff may easily form intimate peer relationships. Personal relationships outside of the work environment may be less intense and gratifying, thus creating dissatisfaction. Intense work relationships such as those similar to survival bonding can, by contrast, create distance in personal relationships with family and friends. AIDS workers often believe their "peers" are the only ones who truly understand their work. Support from friends and family may no longer be as satisfying, a situation which can actually increase stress. Hence, the paradox: when peer relationships are sought for support and intimacy, a strain can result in personal relationships with friends and family.

Intervention

Maintaining a balance of formal and informal supports, as well as an adequate quality of support in one's personal life, seem to be key in reducing stress and burnout in a high-stress environment. Despite substantial prior research, an organizational administrator beginning or expanding an AIDS program would find little information or guidance in the current literature on how to maximize formal and informal supports in order to recruit and retain staff.

Gordin (1987) found the greatest concern for HIV/AIDS providers was fear of being emotionally drained. As discussed at the beginning of this chapter, early in the history of the pandemic, fears of disease contagion and stigmatization prevented health care workers from entering AIDS work (Bennett, 1992; Ross, 1993; Schoen, 1992). Health care workers who had originally feared physical aspects of HIV work now describe psychological aspects as their greatest personal concern (Paradis, 1993; Schoen, 1996).

Also earlier in this chapter, grief overload was discussed as being responsible for worker stress and burnout. Several authors reported a parallel process occurring between worker grief and loss saturation in the work environment (Paradis, 1993; Schoen, 1992). Increased absenteeism, low morale and productivity, and higher turnover rates were reported in AIDS organizations.

Designing strategies which address organizational stress, rather than just individual stress, became necessary to maintain productive staff. Schoen (1992) describes the parallels between organizations constantly changing their course and the experience of stressed workers. Interventions which were recommended to reduce such organizational stress included staff appreciation, acknowledgements, memorial services, staff journals, informal outings, and team building sessions. Such strategies, Schoen asserts, can attend to organizational needs and should be evaluated continually for effectiveness, due to the rapid changes within each work place. Dealing with both personal grief overload and with organizational grief saturation is a necessary process for a successful program.

An organizational stress profile was also the subject of a study by Cushman, Evans, and Namerow (1995). They interviewed social service providers in five large urban medical centers about the stressful aspects of their jobs. Open-ended, self-administered questionnaires were given to more than 100 social service counselors and health educators. A third of the sample characterized their highest stress level as related to AIDS work, another third to heavy caseloads and understaffing, and a quarter of the sample to lack of support, bureaucratic difficulties and inadequate job benefits. Environmental problems such as working in a bureaucracy and staff shortages were also clearly delineated as major contributors to stress.

Stress-reducing mechanisms at these work sites were also identified in Cushman et al.'s study. The effectiveness of stress workshops, rotations away from direct services, and formalized support groups were reviewed. In an unexpected finding, 40 percent of the sample stated they had been offered none of these services. Even though the findings in the study documented the need and benefit of support groups for AIDS providers, few had access to a support group on their jobs. Yet, most respondents state they would take advantage of these services if available. The authors caution that, as work pressures increase, so does overall job stress, which creates a significant decline in worker satisfaction. Without adequate staff support, stress and burnout become even more unmanageable.

To be effective, strategies to replenish AIDS social workers must integrate both internal and external stressors. Yancik (1984) states, "A combination of psychological, situational and social support variables buffers the impact of hospice work stressors" (p. 57). As shown in the literature, work settings require a degree of bureaucratic flexibility and worker autonomy in order to decrease high levels of stress. Conversely, as documented in the social support literature, bureaucratic, inflexible organizational settings create additional stress for staff.

Vachon (1987) sees high staff turnover rates as indicative of organizational dysfunction. Because job satisfaction influences stress and burnout, AIDS organizations can reduce staff turnover by designing interventions addressing these problems. External variables which affect organizational stress include work load, relationships, tasks, and program structure. External stressors, according to Vachon, also include communication problems, role ambiguity, role conflict, environmental stressors, patient characteristics, grief overload, and team problems. Schneider (1987) suggests the following responses to external stressors: limiting changes, encouraging shared responsibility and trusting relationships, providing adequate supervision and support systems, maintaining manageable caseloads, and providing creative ways for staff to grieve.

Driedger and Cox (1991) state there is "evidence... for the importance of co-worker social support in the perception of stress" (p. 197). The authors also assert personal support, such as that provided by spouse, friends, and family, is another valuable asset in buffering stress. Because co-worker support can play a significant role in mediating stress, the use of teams in AIDS work may also conceivably produce successful results. Further, the authors note, shared responsibility and decision-making, task rotation, mutual aid and conflict resolution all can impact staff positively.

Conversely, they found that role conflicts, role ambiguity, breakdown in communication, and competing turf issues adversely affect stress levels in workers.

Ultimately, however, individuals within the organization must take responsibility for reducing and managing their own stress. Self care, relaxation, meditation, recreation, goal and limit setting, and spirituality help prevent burnout (Paradis, 1987). The decision to take responsibility for one's own needs within a high stress environment is essential to reducing the stress experienced in that environment. Thus it is the combination of organizational and interpersonal strategies which promote worker satisfaction, while helping to prevent burnout.

Conclusion

The literature illustrates a rich body of research on the impact of stress and burnout. Factors related to why excessive stress and burnout affect people who care for HIV/AIDS patients have been extensively documented over the last ten years. The gap in this research which remains is to identify what helps to replenish social workers who work with HIV/AIDS populations. In order to better understand whether individual characteristics and/or organizational factors influence the replenishment process of AIDS social workers, a qualitative design was chosen due to a lack of existing research.

The following chapter describes the methodology used to carry out this study, including data collection and analysis of responses to the qualitative interviews.

CHAPTER III

METHODOLOGY

Introduction

This chapter defines the purpose and rationale for this study and describes the methodology and the reasons for choosing a qualitative research design. A description of the sample, respondent selection process, and program sites selected are also included. Additionally, the development of the interview guide and selection of questions which seemed to be most central to the study objectives are discussed. Finally, the process of data collection and analysis are described, as well as the limitations to this research.

Purpose of Study

The purpose of this research was to provide a rich descriptive account of the experience of social workers in New York hospitals designated as AIDS Centers and of the meanings they ascribe to their work. More specifically, the research focuses on worker stress, coping, and replenishment. To describe this experience in the workers' own "voices" I use in-depth, face-to-face interviews which explore how AIDS social workers cope, how they responded to job-related stressors, and whether formal and informal support structures were able to help them mediate stress and replenish themselves.

The research was done in an effort to better understand the ways in which individuals cope, as well as to examine intervention strategies which could reduce stress levels and facilitate retention of experienced staff. In doing so, I hoped to determine whether there is a repertoire used along the continuum from coping through burnout and to what extent, if any, staff could be purposefully replenished. *Replenishment* was the pivotal heuristic concept explored in an effort to identify what types of individual and organizational interventions help sustain and re-energize social workers employed in high-stress areas, such as care of AIDS patients. Finally, I sought to determine whether certain coping strategies or organizational interventions could provide sufficient support for staff to maintain their resiliency in this work.

The literature powerfully demonstrates the stress of AIDS work and the potential for burnout as a predictable outcome. Thus, this research is important in finding methods to deter this process and determine what styles of coping mechanisms or organizational interventions are effective in mediating work-related stressors. How to sustain or replenish staff has yet to be studied, consequently, an exploratory method was used.

Rationale for Research

An increasing number of AIDS patients are requiring social work services in hospital settings. The upward trend of new HIV-infected cases (New York Times, 2003), in combination with the key role experienced social workers play on AIDS care teams speaks to why it is essential to retain trained, experienced staff to provide these complex, comprehensive services.

Previous research has investigated stressful work environments and sought to determine contributors to staff burnout. The literature also examines the type of individual personalities or traits which make one hardy or resilient. However, what has yet to be explored is whether staff can be re-energized or replenished, rather than becoming burned-out. In addition, I sought to determine whether there are organizational replenishment strategies which can help staff remain resilient.

This study is intended to contribute to the literature in two ways: 1) By documenting the continuum of behaviors from effective coping to burnout and determining how staff burnout can be prevented; and 2) By developing a conceptual framework which defines personal and organizational mechanisms of replenishment. The first task is descriptive; the second, theoretical.

The costs of recruiting, hiring, and training AIDS social workers can be very high. In addition, given the complex, ongoing care required for AIDS patients, the need to retain staff is critical. As previously mentioned, AIDS social workers are key members of the multidisciplinary care team. In order to maintain staff, there is a need to understand how social workers are replenished. Learning more about the value of social support relationships and organizational supports can begin to explain how stress is mediated or buffered in these stressful jobs. Examining how staff copes and whether the organization plays a part in buffering stress is of value for personnel in other high stress care environments, such as palliative care, emergency services, and intensive care units, as well as to workers in other disciplines in these areas.

Finally, as a social work administrator, as well as a researcher, I was motivated to learn more about the effects of chronic stress and how to reduce it. Understanding the role which supervisors, social work departments, AIDS Centers, or larger organizations play in staff coping and burnout was important to me and to the social work field in general.

Sample Selection and Development of the Research Instrument

The focus of this research was to study social workers employed in New York City hospital-based AIDS Centers. The study was conducted in 1999 over a six month period. At the time of the study 17 hospitals were AIDS Designated Centers (ADCs). There is substantial diversity between these programs, including size, number of social work staff assigned to the AIDS Center, caseload size, diversity of support mechanisms, years of designation, and level of program activity. Such diversity allows for a broad sample, representative of the different centers and of their variability in program staffing, organizational structure, and years of designation. Information regarding which hospitals are designated as AIDS Centers, and who to contact at each AIDS Center, came from the New York State Department of Health, AIDS Institute, as well as from my own professional knowledge of programs throughout New York City.

Because this was an exploratory study, I attempted to interview social workers in several programs, thereby allowing the capture of a wide range of individual and organizational influences. Given my previous experience as the social work coordinator for the AIDS Center at one designated hospital, various contacts were available, based upon previous work-related relationships.

For study purposes, contacts were made at ten AIDS Centers in New York City. It was apparent in this process many AIDS social workers within these settings were interested in learning more about stress and coping, and were open to participating in this study. Internal Review Board approval from the CUNY Graduate Center was obtained prior to initiation of this study.

First, I sent a letter of introduction to an identified contact person at each hospital to gain entrance into their center and to enlist their support in obtaining as many interviews with social workers on their staff as possible. Once the initial letter of introduction was sent, there was a follow-up phone call to the designated individual. Frequently, the person who was the initial contact was the AIDS social work supervisor, but this varied, depending on the size and organizational structure of the program, (i.e., this was not true in smaller programs where there was no AIDS supervisor). In some cases, there was a matrix reporting system to the AIDS Center administrator rather than to social work. In either case, once the name and address were secured, a letter of introduction was sent indicating a date and time I would call them directly. Due to the sensitivity of the subject matter, permission to tape and assurance of confidentiality were explained clearly throughout this process. Also, because I was involved with managers in other AIDS Centers, staffs needed to be assured their interviews were totally confidential.

After obtaining approval from various supervisors, I contacted each staff person by phone to ascertain their interest in participating in this study. If they responded positively, a 90-minute interview time was scheduled at the time and location most convenient to them. In almost all cases, the selected interview location was their office. Interviews began with an introduction to the research and request to proceed with and to tape the interview, which was secured from all participating subjects.

Pilot Interviews

I conducted two pilot interviews during the process of questionnaire design. These social workers were told the purpose of the interview was to refine the instrument, rather than to generate research findings. Two participants helped to refine questions that were unclear and to suggest others which would better elicit the information desired. Some questions were changed as a result of the pilot interviews. For example, questions designed to reflect changes over six-month intervals in job expectations or satisfaction, were rephrased into questions that asked about high points and low points in AIDS work over the course of their present job.

The pilot interviews enabled me to develop an instrument which could capture the dynamic process of coping and replenishment. The interview guide provided a framework for the questions asked in the final instrument.

The Interview Guide

According to Patton (1987),

> An interview guide is a list of question or issues that are to be explored in the course of an interview. An interview guide is prepared to make sure that essentially the same information is obtained from a number of people by covering the same material. The interview guide provides topics of subject areas about which the interviewer is free to explore, probe, and ask questions that will elucidate and illuminate that particular subject (p. 111).

In this research study, I developed an open-ended interview guide with 15 questions, as well as prompts to accompany each one (see Appendix 1). Prompts were used to encourage a substantial range and depth of responses. The guide focused on the following substantive areas:

1) Expectations and reasons for working in AIDS
2) The high point of the work
3) The low point of the work

4) How stressors impact job performance and satisfaction
5) Coping abilities and what helps to buffer stress
6) Why they stay or why they would leave AIDS work
7) What organizational supports already existed or, if available, could reduce stress

Questions were posed encouraging subjects to self-assess their individual resiliency and coping tactics. Particular attention was given to what subjects saw as mediating or exacerbating their stress levels and the role the organization played. Understanding individual expectations and decisions to work in AIDS were sought to determine whether this had any bearing on their coping and/or feelings of burnout. In addition, the instrument was developed to explore whether social workers experienced stress and coping on a continuum which could be measured in future research as interventions are introduced. Ultimately, the interview guide sought to identify the means by which those who chose and remained in this work replenished themselves.

As Patton (1987) points out, "Every good interview is also an observation" (p. 139). While the interview guide provided a useful tool, the observer is also key to successful interviewing. Yin (1984) describes a successful interviewer as one who asks good questions, is a good listener with a grasp of the core issues, and is flexible and unbiased by preconceived notions (pp. 56, 57).

In addition, for a good interview, Patton asserts, "validity and reliability depend to a great extent on methodological skill, sensitivity, and training of the evaluator" (p. 8). Given my extensive background in direct AIDS work and supervision of AIDS social workers, I chose to interview each respondent. In addition to being a skilled clinical interviewer and observer, I was very knowledgeable about the subject matter and had a grasp of what was involved in this type of work. Yet, I was careful to be open and not direct the interviewee in any predetermined direction based on former experience or personal biases. Additionally, during the interviews, I was able to pay attention to the subtleties and non-verbal communication of each participant, which provided a rich and meaningful portrait of each worker's experience.

Demographics

The sample for this study consisted of 19 social workers, all with at least a Master of Social Work degree. Ages ranged from 23 through 63 years old, with a mean age of 42 years. All subjects had worked at least one year in their present position. The range of AIDS experience was from 1.5 to 16 years, with a mean of 6 years. Each ADC had at least five social workers employed in AIDS, some having up to 10. Years of social work experience ranged from 2 to 37 years, with a mean of 10 years of experience. There were 12 female and 7 male subjects. Thirteen of the total sample stated this was their first job in AIDS; six had worked in other AIDS positions. 12 people earned salaries ranging from $40,000 to $50,000. A total of six social workers earned $50,000 or more. Caseloads varied significantly and were difficult to compute, given the variability of assignments, (i.e., some social workers only worked on an inpatient service as opposed to a continuity model).

Settings

ADC sites were approached by calling social work managers (or, when requested, directors) to gain access to staff. In two centers where the manager was agreeable, their entire group refused, citing confidentiality concerns. In total, seven ADCs participated. All of these organizations were academic health centers which cared for similar patient populations and had been designated for several years. Although the number of social workers and their level of experience in social work and AIDS work varied, there were more similarities than differences between programs. All had case management programs in place for patients and formal or informal support structures for workers. Because more than one social worker was interviewed at each site, I was able to identify some subtle variations from program to program. Although these differences may have influenced how social workers responded, they were not the focus of this research. While the settings variably influenced some worker experiences (such as relationship with supervisor), I was compelled to study the collective experiences of the entire sample with regard to stress, coping and replenishment.

Qualitative Design and Data Analysis

Emphasizing epistemology, Patton (1980) views qualitative research methodology as involving three basic components:

1) Holistic view – understanding the phenomenon in its entirety
2) Inductive approach – finding general patterns, without imposing a structure or assumptions on the inquiry
3) Naturalistic inquiry – understanding the information in its natural environment

Holistic View

In this study, a qualitative method was most appropriate for describing the experiences of AIDS social workers. On this point, Polkinghorne (1991) suggests qualitative research is useful in the "generalization of categories for understanding human phenomenon and the investigation of the interpretation and meaning people give to events they experience" (p. 112). I decided to use more than one ADC to give depth to the findings. It also allowed for differences in programs to emerge.

Inductive Approach

Rudestam and Newton (1992) stated, "The instrument of choice for the naturalist is the human observer" (p. 76). In this study, I collected data from subjects who are most involved in AIDS work. By describing their stressors, experiences, coping mechanisms and abilities, and efforts at replenishment, the social workers become key informants to this study. The interviewer documents the data and becomes the human observer to this study. Participant observations give the evaluators an opportunity to use "raw, descriptive information about programs and people in programs" (Patton, 1987, p. 7).

Describing the "experience survey" as a study type, Tripodi, Fellin, and Meyer (1969), advocate "interviewing participants who are closest to the area of exploration or most knowledgeable about the work" (p. 46). Clearly, AIDS social workers are on the front lines of patient care; they have daily face-to-face contact with patients and their families. Generally, social workers work with patients from diagnosis to death and use a continuity of care or case management model. Social workers are often the primary support for patients, families, and staff. Documenting their experiences creates an opportunity to collect data on coping and burnout in AIDS work.

Qualitative methodology attempts to organize data around themes and categories. The interview guide for this study was developed with questions to elicit an in-depth variety of responses necessary to identify the themes associated with coping and replenishment. Because the research explored different programs, supports, and structures, data collection is more easily extrapolated to different settings and worker experiences.

Naturalistic Inquiry

Patton (1987) reflects, "Naturalistic inquiry focuses on program processes, documenting variations and differences between various participants' experiences and outcomes" (p. 14). According to Lincoln and Guba (1985), "what is at issue is the best means to make sense of the data in ways that will facilitate the continued unfolding of the inquiry and, second, lead to a maximal understanding of the phenomenon being studied" (p. 224). Accordingly, Lincoln and Guba developed guidelines for performing a naturalistic study:

1) Determining a focus of inquiry
2) Determining a fit of paradigm
3) Determining a fit of paradigm to substantiate theory selected to guide the inquiry
4) Determining where and from whom data will be collected
5) Determining successive phases of the inquiry

6) Determining instrumentation
7) Planning data collection and recording modes
8) Planning data analysis procedures
9) Planning logistics
10) Planning for trustworthiness (p. 225)

In this framework, the researcher thoroughly considers all aspects of inquiry before implementing a naturalistic study. Underlying assumptions and how these fit into methodology, as well as purpose, selection process, and parameter of data collection need to be assessed before final methodological decisions can be made.

According to Patton (1987), the process of qualitative data collection consists of three different processes, which are as follows:

1) The informal conversational interview
2) The general interview guide approach
3) The standard open-ended interview (p. 109).

For this study, the method of data collection I selected was an open-ended interview guide used to elicit the perspectives of AIDS social workers by means of face-to-face, in-depth interviews. Once the data collection process was completed, the data analysis became the next consideration.

Data Analysis

Interviews were taped, professionally transcribed, and reviewed for data analysis. Although there is an additional expense involved in tape recorded interviews and the costs of transcribing them, the added value this method provides in the data analysis offsets the additional expense.

Interview notes were examined in conjunction with the transcriptions to clarify meaning, enrich details, and ensure no information was excluded. Common themes were then identified and categorized through a data-coding process. Although themes emerged during the interview process as well, these were refined further once all the interviews were completed. I identified similar patterns in the data, as well as outliers or differences. Using a creative yet flexible process, categories were collapsed into conceptual themes reflecting all responses. As described by Glaser and Strauss (1967), "The constant comparative method requires continual revision, modification, and amendment until all new units can be placed into an appropriate category and the inclusion of additional units into a category provides no new information" (Rudestan & Newton, p. 114). Categories were reviewed until they were able to make sense once all the data was collected and coded. Coding responses from the transcriptions allowed for logical sequencing to determine the conceptual framework for the overall analysis. "Comparisons are made continuously among categories until there is a theoretical saturation; i.e., no new categories can be formed" (Tripodi, Fellin, and Meyer, 1969, p. 47). In this study after the completion of 19 interviews, responses were becoming repetitive. The stories being told in the interviews gradually formed a pattern where explicit themes emerged. When no new information was shared, the data collection phase was concluded.

Limitations of Research

There are inevitable trade-offs associated with any research design. Yet, the lack of previous exploration in this study domain made qualitative methodology a clear choice. Patton (1987) believes an important limitation to qualitative interviewing, recording, and analysis are the time and expense involved in the labor-intensive data collection and categorization. Another limitation, encountered while conducting this research, involved the researcher's personal involvement in data collection. I worked in an administrative capacity in one hospital and had substantial contact with managers there and in other hospitals. Therefore, I frequently had to reassure respondents about issues of confidentiality and had to scrupulously keep all information anonymous. Despite my best efforts, subjects expressed some fear this information would be shared with their managers and concern about what the ramifications would be on their jobs. This seemed to be resolved with my continued assurances and their desire to contribute to a study they believed would benefit AIDS social workers in the future.

Qualitative analysis inevitably involves enormous amounts of information, which, ironically, is also a limitation. As a result, some warn "the researcher may become the 'victim' of 'data overload'" (Rudestam & Newton, 1992, p. 113). The coding process involves putting data into manageable categories which identify and describe discreet areas of information. One can become overwhelmed with the data before such categories are defined. In addition, the categories must be reliable and the coding process replicable. Both are challenges for the qualitative researcher.

One major limitation of this study is the interviews were completed in 1999, reflecting responses from AIDS social workers during that time period. AIDS has changed significantly over the last several years due to advances in medical treatment and pharmacological interventions. As previously indicated, the disease has moved from a terminal illness to a chronic illness with no cure. Also, all respondents worked in New York City in AIDS Designated Centers which does not necessarily reflect responses of social workers from other parts of the country, including those working in more rural settings.

Conclusion

This chapter provides an overview of the research sample and site selection process, instrument development, data collection, and, finally, data analysis. The next several chapters will present the findings of this research. Chapter IV describes the findings related to why social workers choose to work in AIDS and what impact this decision has on their expectations and job satisfaction

CHAPTER IV

JOB EXPECTATIONS AND THEIR IMPACT ON AIDS SOCIAL WORKERS

> Others who don't do this type of work can't imagine
> why anyone would voluntarily (enter AIDS work)
> ...to get this close to human misery.
> Quote from an AIDS social worker

Introduction

In describing their jobs, AIDS social workers state they knowingly chose to work in a field which "brought them so close to human misery." Yet, the present study discovered work expectations play a role in workers' job satisfaction. Those who had anticipated a supportive team, as well as a structured, supportive work environment, had more job-related stress and potential for burnout when these were not met, than did those who had entered the field without such expectations. This chapter will present the reasons social workers gave about choosing to work in AIDS; it will also describe how social workers' expectations when entering AIDS work can impact job satisfaction.

Conceptual Framework

According to Schernoff (1990) every social worker will be touched by HIV/AIDS at some point in their career. Lesbian and gay social workers have been at the forefront since early in the epidemic. Yet many of these early pioneers in AIDS work have been personally infected and affected by HIV/AIDS and can no longer do it alone. In order for social workers to continue as leaders in this field, organizations need to understand why social workers choose AIDS work and what factors impact their job satisfaction and keeps them replenished.

Two decades into the AIDS pandemic, and with a great deal of knowledge about what to expect in this work, AIDS organizations are able to provide a realistic picture of AIDS work to prospective staff. Such realism when hiring may also help prevent some stress and burnout of staff. Alternatively, creating unrealistic expectations or not meeting social workers' expectations for their jobs, can unknowingly add to the burden of this work.

According to Egan & Kadushin (1995), "The definition of the role of the social worker is based on his/her perception of the job and the expectations that others have of him/her" (p. 58). Hence, defining realistic job expectations when hiring can help create staff who are clear about what the organization expects from them, as well as what they can expect from the organization. Paradis (1987) found "Discrepancy between expectations and reality can be a source of severe distress and burnout" (p. 1). Therefore, determining what social workers expected when they entered AIDS work and whether these expectations were being met in their current positions, represented the conceptual underpinning of several interview questions in the present study. Questions were asked in this study to determine whether they had any unmet expectations and whether this had any bearing on their level of work stress or job satisfaction.

Similarly, Sotile and Sotile (2002) discuss "interplay between normal and work-related attitudes that provide unrealistic expectations" (p. 67). This interplay between negative stress which can lead to burnout and unrealistic work expectations may be avoidable. Further, hiring practices which include honest conversations about what to expect from the job and what the job can offer may help to avoid this source of added stress. In the early stages of the job, supervisors who discuss with employees whether their initial expectations were being met may still have an opportunity to realistically align expectations with workers actual experiences.

Sotile and Sotile also describe the basis of a "psychological contract" within the medical profession, a contract between physicians and their expectations of their jobs. The authors assert physicians feel double-crossed and become at greater risk for stress and burnout when this contract is broken. As a result, they can lose trust in their workplace, causing negative consequences in both performance and sense of well-being. The authors also found some of these expectations may involve work autonomy, a reasonable workload, and appreciation and support in their work. The same may hold true for social work expectations and how they relate to job satisfaction and the perception of work stressors.

Reasons for Choosing AIDS Work

Social workers choose to work with AIDS patients for several reasons. Although the reasons may vary, the expectations may remain the same. Following are responses to this inquiry:

Personal Reasons

The majority of social workers reportedly decided to work in the AIDS field for very personal reasons. Although there were some variations in their responses to this question, the reason most gave for choosing AIDS work was because they saw it as being especially meaningful to their personal lives. One person described it as doing "God's work"; another believed such work helped to make them a "better person".

Another frequently mentioned reason social workers decided to work in an AIDS position was to achieve a sense of community affiliation. For example, having close ties to the lesbian, gay, bisexual, and transgender (LGBT) community were cited as a reason they chose to do this work. For those affiliated with the LGBT community, their own battle with AIDS often preceded choosing to do AIDS work. AIDS was attacking their community; many friends, family members, and lovers were infected or had died. There was a sense of urgency and a need to join forces or fight back against a common enemy. As one respondent put it, "I am identified with the gay community and saw a lot of people dying around me. I wanted to fight back, so I decided to work in AIDS."

In addition to association with the LGBT community, some social workers discussed "bearing witness" to the AIDS pandemic as their reason. Personal losses of friends, lovers, and family members to HIV/AIDS translated, for them, into a desire to work in AIDS. For one individual, the choice was extremely personal and close to home; he acknowledged his HIV-positive status during the course of the interview, saying "I found out my HIV status in 1988. I decided to go to graduate school to do something about AIDS on a professional level. I wanted to be alive in 1998."

Several other subjects described a commitment to AIDS work emanating from personal losses. As one social worker stated,

> My best friend died in my arms of AIDS. I'm sure that plays into it, too. It certainly makes me sensitive about what it means to love somebody with AIDS and go through their sickness, and their illness, and their struggles. I was part of a team that took care of her at home. I know it personally and professionally.

For others a sense of "protecting themselves" or a loved one against contracting HIV/AIDS was a factor in their choice to do AIDS work. For example, one subject said her reason for working in AIDS was to obtain specific and timely updates on contracting the illness. She stated, "I have a teenage daughter who I am scared for. I wanted to learn more about what she should be careful of."

This desire for self-protection appeared to have a quality of "magical thinking" about it, as though by working with AIDS patients they or a loved one would avoid being infected. One social worker remarked, "As a gay man, I was afraid that I would be infected and that somehow by doing this work I would be safe."

Although several other subjects expressed the same sentiment, they admitted their beliefs were not rational. Clearly, they were knowledgeable about HIV routes of transmission, but somehow felt getting this close to the misery and doing this important work would protect them from infection in their personal lives and keep them physically well. Rational or not, several respondents said they felt if they did this important work, they might be rewarded in some way, either by not becoming infected or by protecting loved ones from this devastating illness.

Professional Reasons

The professional reasons cited for choosing to work with AIDS patients were related to the challenge of the AIDS work itself. Terms such as "new" and "cutting edge" were used to explain their interest. One worker summarizes these types of responses by saying, "I liked AIDS work because it was challenging, because it was difficult, because it didn't have much tradition, and because the services were being shaped by consumers." For others, a dedication to working with women, families, or the impoverished was mentioned. Professional values and other professional interests were also mentioned. These included wanting to do death and dying work, seeking ego-fulfillment, or achieving increased feelings of self-worth.

Accidental Reasons

While the majority of social workers interviewed chose to work in AIDS, a few did not. These workers described themselves as entering the work "accidentally". Reorganization and reassignment within their institutions, or work with AIDS patients being the only available job opening at the time, were among reasons given. Even those who felt they had stumbled into this work, however, commented on other, more active motivators for accepting these positions i. e., professional challenge.

Combination of Personal and Professional Reasons

The most frequent reason given for entering AIDS work involved a combination of personal and professional motivators. Often personal reasons combined with political viewpoints, such as being identified with the LGBT community or the economic advantages of working in a hospital. Regardless of the reasons given for choosing the work, they did not seem to correlate to whether these workers coped differently with the work or whether they chose to stay in AIDS work.

Job Expectations of AIDS Social Workers

There were three general sets of expectations which all of the social workers had about choosing AIDS work; these were:

1. Having intense relationships with patients, especially around death and dying work
2. Having work which would be stressful but rewarding (both personally and professionally)
3. Working within a supportive, multidisciplinary team

Intense Relationships with Patients

Subjects' expectations were focused primarily on working intensively with patients and their families. The meaning they ascribed to the intensity of these relationships derived from working with patients throughout the course of their illnesses, which often included death and dying issues. Social workers anticipated working within a continuity of care model allowing them to follow their patients regardless of their treatment location, i.e., in the hospital or as outpatients. This model enhanced the intensity of the social worker/patient relationship in their expectations, because social workers would work with patients from initial diagnosis to their death. One subject stated, "I wanted to work with the terminally ill and to be able to form relationships that were more than short term." Another said, "I expected to be able to touch people's lives at a vulnerable time."

Hence, longer term, one-to-one relationships which were focused around clinical care was the main reason for entering AIDS work. In addition, there was an implied belief that working with the terminally ill would lead to strong feelings of personal satisfaction in their jobs. As one person stated, "Going in, I felt like that was going to be a big issue because there would be lots of concerns about death and dying, you know, so that would be stressful." Another said, "I expected that I could be spending a lot of time at the bedside of a dying patient and that I would always be in a race against time, always trying to anticipate the changing needs, and it forced the system to work faster for patients."

Stressful but Rewarding Work

Feelings of intense personal satisfaction were clearly expected by most of the respondents upon entering the AIDS field. Although workers anticipated the work would be stressful, their overriding belief was that it would also be fulfilling. Typically their pattern of responses included both aspects: the work would be personally rewarding, but also emotionally challenging.

One subject described her relationship with her patients as emotionally draining, but incredibly rewarding. She went on to say there is a "richness" of interaction between patients and staff, which is exactly as she anticipated. Others defined their work with phrases such as "amazing and intensive" and "inspired by patients".

Subjects also indicated they expected to form immediate bonds with their patients. In fact, as one respondent commented,

> I think that the really ill patient is where I find the most satisfaction. I think it's very difficult and I recently was there when one of my long-term, very intensely close patients died, and that was very, very difficult, but also very, very rewarding as well. And I think that I would say that the dying stuff is appealing to me.

Working within a Supportive Multidisciplinary Team

One way subjects expected to be replenished in their difficult work was through support from their multidisciplinary teammates. The team concept was frequently mentioned as a reason for choosing AIDS work and seemed to accompany an expectation of a "structured environment with a lot of support." Accordingly, several social workers expected a supportive environment and team members that would be nurturing. One respondent summed up this sentiment by saying, "I have an opportunity to work closely with multidisciplinary health care providers, sharing informally, and having similar goals."

Sadly, although social support was acknowledged from co-workers, many of the respondents felt that, with the exception of their co-workers, there was little institutional support provided to them, i.e., little availability of staff support groups.

Overall, social workers who expected personal satisfaction in their jobs generally experienced them as meeting their expectations. On the other hand, those who expected organizational support were more apt to be disappointed. By implication, then, the role of the organization in creating realistic job expectations becomes an important factor in linking AIDS social worker expectations with job satisfaction.

Unfulfilled Expectations

Subjects who described unfulfilled expectations most often mentioned the lack of team support and supervisory support, as well as increased organizational pressures.

Team Support

In view of the stress of AIDS work, several subjects reported being particularly disillusioned by the lack of team support they had received, compared to what they had initially anticipated. They incorrectly assumed some type of support structure would be in place within their organizations, given the challenges inherent to the job. Conversely, rather than finding co-workers to be supportive, some subjects described their teams as fractured or non-functional. Others reported there were times when the multidisciplinary team was unsupportive, but their fellow social workers filled this void. One subject commented:

> I felt given the work, staff would be supportive of each other. I thought they would be nurturing and understanding. Instead there seemed to be no time for support. In trying to make time, like staying late, it was at my own expense. In fact, it's a hostile team. We are at each other's throats except for my social work co-workers. When we talked, we had the same fears and anxieties which helped us to bond and support each other.

Organizational Pressures

Some subjects who described unfulfilled expectations focused on stressors related to organizational pressures. Several said increased caseloads and pressure to decrease the length of patients' hospitalizations created significant frustration, because they had insufficient time to work directly with patients. Instead, workers felt they spent too much time making systems work, planning for discharge from the hospital due to limited community resources, and being pulled to work with general medical-surgical patients, rather than working with AIDS patients. As one worker put it, "I spend more time getting patients hooked up with services as patients have gotten more indigent." Translating this further, she said, "I spend more time with chronic case management, rather than death and dying, as I previously anticipated". Increasing the quantity of work, while decreasing what subjects perceived as the quality of their work, created feelings of frustration and, at times, job dissatisfaction.

Supervisory Support

A distinction was evident in responses from a few subjects who perceived variation in support due to supervisory arrangements; i.e., social workers reporting through the ADCs versus through a Department of Social Work. AIDS Centers are often referred to as product lines or disease centers. As one respondent conjectured:

> I feel strongly that being under the Social Work Department really waters down a lot of AIDS team work. I think that if we were a product line, for example, if the AIDS team reported directly to the AIDS Center and didn't for example, Social Work, I think that would make us stronger and more focused.

Although study respondents framed their responses in terms of reporting relationships/structures, supervisory support was more frequently correlated to the quality of their relationship with their supervisor. Therefore, whether the supervisor worked within the AIDS Center or the Department of Social Work was less relevant than whether or not the supervisor was seen as supportive and an advocate for their work.

Structure was linked with stability in the experience of one worker, who commented:

> The stability (expectation) has not been met. The supervisor who was making that assurance left about three months after that, maybe less. I think throughout the time I've been here there has been a series of institutional crises or changes that have made it very unstable and somewhat difficult to work with. I think the year after I started working here there was a threat of lay off. In particular, I was told by the director I would be laid off.

Reorganizations, fiscal crises with threatened lay offs, and changes in management were also linked to unfulfilled expectations and job satisfaction.

Conclusion

Job expectations and reasons for choosing AIDS work were found to be closely related. Study subjects' expectations generally had three attributes: expectation of intense relationships with patients and families, of stressful but rewarding work, and of working as part of a supportive, multidisciplinary team. Unfulfilled job expectations negatively impacted job satisfaction and created additional stress for AIDS workers.

As indicated in the literature, reasons for entering the field of AIDS work, and whether those reasons support realistic job expectations, can impact later job satisfaction as well. In the present study, reasons for entering the AIDS field were both personal and professional, and in some cases, a combination of both. According to respondents, stress and job satisfaction were not linked to their reasons for choosing AIDS work. In fact, two significant reasons given in this study were: 1) a belief that AIDS work is very important and would somehow "spare" workers from contracting the illness; and 2) a strong self-identification with the LGBT community.

With regard to the first reason, the importance of the work, some described it as "God's work" and felt doing such work would somehow protect them or their families from contracting HIV/AIDS. Some who described the work in these terms were aware of the unreasonableness of such magical thinking, but nonetheless felt such protection would be their reward for the difficult work and would help them to avoid transmission, or if already infected, would keep their disease from progressing.

For many, there was also a strong identification with the LGBT community, either because they were a part of it or because of numerous or significant losses of friends, lovers, and/or family members to HIV/AIDS. These subjects discussed the disease as an enemy, and their work as helping to fight the battle against a deadly foe. For them, choosing to work in the AIDS field was described as both a personal and professional "calling". Their commitment to their jobs, and the clarity of their job expectations, were perhaps more realistic than those who gave the first reason as the one most influencing their decision to work in the field.

Supervisory and team support, also part of subjects' job expectations, reportedly added to increased stress levels and job dissatisfaction when they were not available. Similarly, organizational pressures also created increased stress levels, especially when they decreased the time workers spent in direct patient care. Of such organizational stressors, threats of layoffs and changes that would impact work relationships were found to create the most frustration and additional stress.

Thus, overall, the study revealed that, while unfulfilled expectations may be unavoidable at times, when job expectations are presented realistically and can be met, staff have a much higher rate of job satisfaction and ability to replenish themselves. Increasing supervisory support, while decreasing organizational pressures, helps AIDS social workers maintain a level of hardiness. Although replenishment can come directly from the intense and satisfying work, meeting workers' expectation of being part of a supportive team also plays an important role.

CHAPTER V

ORGANIZATIONAL STRESSORS ON AIDS SOCIAL WORKERS

> It's not working in AIDS; it's not working with people who are dying, that's not what it is. It's all the other stuff.
>
> Quote from an AIDS social worker

Introduction

Organizational stressors have been described as one of the major factors in depleting energy and producing stress for AIDS social workers. High pressure, bureaucratic work environments which limit flexibility and worker autonomy were viewed as low points in AIDS work. Job dissatisfaction was tied to increasing managed care demands, financial constraints with the threat of lay offs, and patient-related stressors. The work stressors inherent in the care of AIDS patients are further intensified by a lack of organizational support and provision of necessary, specialized training. The following chapter will describe these organizational stressors as defined by AIDS social workers participating in the present study.

Conceptual Framework

The organizational context for AIDS social workers is the hospital. As previously documented, social workers in hospital settings are at high risk for burnout. However, understanding how work stress depletes staff can help to identify strategies for their replenishment. Attending to the need for replenishment, Paradis (1987) remarks: "Providers are at high risk for the physical and psychological patterns related to stress; if not replenished they will not be able to adapt and become exhausted" (p. 5).

Research of care providers working in high stress areas, such as trauma, showed many who experience secondary trauma from their work, meaning they experience similar symptoms as their traumatized patients, Rosenbloom, Pratt, & Pearlman (1995) suggest those whose work is

> very stressful are further impacted by the environment in which they work. Depending on how the organization responds to their stress, staff may feel supported in their work or conversely believe they are being undermined if not supported (p. 76).

What individuals perceive as stress is related to the amount of control they have over their work. The perception of individual control is a key factor in how health care workers experience stress within the organization. In fact, Sotile & Sotile (2002) describe a study of 300 employees who showed higher levels of burnout, depression, and job dissatisfaction based on high job demands and low level of control. Thus, jobs requiring a great deal of responsibility but providing little control or autonomy over one's work, create increased burnout and job dissatisfaction among workers. Additionally, "Research has shown that when a lack of social support is added to the high demand/low-control paradigm, the toxic effect is amplified" (Sotile & Sotile, p.12). Therefore, increasing the perception of control over one's work, while providing social support, can help to diminish this toxicity and avoid burnout.

Working within a medical setting, such as social workers' hospital environment, creates additional challenges. According to Pockett (2003), the culture of hospital work, especially social work, must deal with the "ambiguity between the medical model and the psychosocial model of care" (p. 4). The psychosocial model is guided by a holistic approach, which focuses on the client's right to self-determination and control. While the medical model is guided by imposing care and cure upon patients, death is perceived as a failure.

Levy and Gordin (1987) observe that,

> [AIDS social workers function] within the world of medicine staff activities are directed towards producing medical cure, and such organizational components as a hierarchical division of labor, an ethical system for valuing life, and the technological procedures of medical practice shape the productive process. Within medical ideology, death is the final enemy, and dying serves as a visible sign of staff failure (p. 32).

Stress related to AIDS work can parallel that of the organization. For example, the symptoms of "loss saturation" in organizations closely parallel those on individuals (Schoen, 1992). To address the impact which grief overload has on staff, the organization must create a culture open to grief responses and create structures which support the expression and symbolic significance of these feelings.

According to Ross (1993), "General work stressors as well as the pressures of working in medical settings, may be exacerbated by issues that may be unique to, or particularly prevalent in, organizations that care for HIV/AIDS patients" (p. 93). Time pressures, large workloads, and poorly defined roles can add to this stress. Ross also found social workers' low salaries, lack of promotional opportunities, inability to influence policy within the organization are additional stressors. AIDS adds yet another layer of stressors with issues such as prejudice, stigma, fear, and health care disparities. Ross found patient stressors include duty to warn, notification of partner risk, ethical decision-making, and complex psychosocial issues such as rational suicide and mandatory HIV screening.

Hence, due to the type of work and the inherent organizational stressors AIDS social workers encounter, it is extremely important to provide support and structure to replenish them. This does not mean, however, individuals are not responsible for maintaining their own emotional health. "One of the guiding principles of preventive stress management is that individuals and organizations are responsible for health and well-being" (Nelson, Quick, & Simmons, 2001, p. 358).

The issue of responsibility will be discussed later in more detail.

Stress Factors

Organizational Pressures

The organizational structure, stability, and amount of support were found in the present study to alleviate stress or to compound the level of stress experienced by AIDS social workers. Stress derived from organizational factors was experienced as cumulative in how social workers felt they were coping. In addition, social workers who reported experiencing both intense patient pressures and organizational stressors were more likely to think about leaving AIDS work; those reporting one type but not the other were less likely to leave. One respondent who was particularly stressed by organizational factors commented:

> I have to say a lot of my low points came not so much from working in AIDS, but it had to do with lots of organizational changes, like when I was told I was laid off. It dragged on for three months while they tried to make a decision and figure out what they were going to do. So there was a three-month period I was extremely tense, worried, and unsure about what was going to happen. It was the combination of working with people with HIV and all the stress that comes with that, and then when there's stuff thrown on top of it, that stuff can be difficult to tolerate.

Organizational instability and potential lay offs were found to be substantial stressors for at least three social workers. In addition to the usual stressors of working within a bureaucratic environment, their situations were complicated further by changes in administration or supervisors, increased caseloads, and decreased length of hospitalization stays for patients. As workloads increased and timeframes to do their work decreased, their frustration and stress levels rose.

Resource Constraints

Financial constraints due to decreasing reimbursement rates and higher costs further compounded the stressors related to working within a bureaucratic setting. An expansion of managed care added stress that impacted patient care directly and increased the paperwork necessary for workers to do their jobs.

Several study subjects related the onset of managed care with increased work-related stress. One said, "There is a focus on quantity, not quality." Managed care companies started questioning length of stay for hospitalized patients and demanded more documentation of the care provided. These bureaucratic demands seemed to leave social workers feeling a loss of control, and even powerless at times. One social worker discussed feelings of powerlessness. "And I feel, I guess, much less able to control the things that are happening institutionally, and that feels more stressful to me because of the powerlessness of it."

Time Constraints in Patient Care

Contrary to what one might expect, the deeply felt lack of control over a patient's death caused much less stress for study participants than their sense of powerlessness over organizational functioning. There was an acceptance of the outcome of the disease, but there was extreme frustration about their lack of organizational influence.

As discussed previously, although working intensely with patients can be a high point in AIDS work, doing such work with decreased timeframes and increased bureaucratic demands can neutralize, and ultimately, erase the inherent rewards. One social worker said, "The focus on quick discharges and decreased hospital stay allowed less time to get to know the patient."

In the eyes of AIDS social workers, good patient care requires intense personal relationships with patients. Because delivery of quality care appears to be what sustains or replenishes social workers, barriers which prevent such intense relationships with their patients become frustrating rather quickly, displacing professional satisfaction and a sense of accomplishment. Stress levels increased even more when the social worker was given less time to plan for post-discharge needs, a situation intensified by diminishing community resources.

Diminishing Community Resources

A few subjects likened community agencies and services to an external bureaucracy. One worker stated, "I have had particularly bad times dealing with external bureaucracies, such as the Division of AIDS Services (DAS) and the food stamp office saying nobody is in charge." As AIDS patients become more medically complex and are living with the disease longer, planning for post-discharge needs also becomes more time-consuming and complicated.

Expediting services through myriad community agencies was seen by participants as stressful. One social worker was frustrated by the lack of access to essential services through agencies such as DAS, Medicaid, and Social Security. Most agreed both internal and external bureaucratic systems could be equally frustrating and related this connection to managed care. "We are so busy pushing paper that we are unable to adequately care for our patients." Interestingly, several respondents connected the increasing demands of internal and external bureaucracies with feelings of powerlessness and loss of control. "I feel less able to control things that are happening institutionally, creating more stress because of the powerlessness of it." The stress buffering effect of helping their patients negotiate through the "system" was eroded due to the increasing paperwork and lack of time to work directly with patients. The role of the organization also seemed to play a key role in the perception of other stressors as well. Organizational instability and administrative changes added to a high stress level. One person said, "My low point is now, and that has to do with changes in administration and the prospect of lay offs."

Low Points in AIDS Work

The difference in participants' responses may be related to their initial job expectations. For example, respondents who had expected the organization would provide support systems, and/or a structured work environment were disappointed when these expectations were not met. Workers who anticipated support from administration often felt they were left "holding the bag, trying to be everything at once."

Interestingly, although some patients were seen as difficult, e.g., active substance abusers, and at times sources of stress, subjects did not see patients as a low point in their work; it was just the opposite. Working with patients seemed to mitigate the effects of stress. As one person said, "It's not working in AIDS; it's not working with people who are dying, that's not what it is. It's all the other stuff." The majority of the study respondents echoed that sentiment.

When participants described the organization as a low point in their work, they focused on a lack of administrative support, poor supervision, and/or a lack of leadership. As mentioned earlier, a majority of them expressed heightened stress levels with increased workload demands, which were compounded by administrative changes or lack of support. Hospital mergers, administrative reorganization, and erosion of the role of social work in hospitals also were mentioned as stressors. One respondent focused particularly on the diminishing role which social work played in the hospital, "My low point has to do with where social workers are in the hospitals and whether or not they'll be kept...and that goes across the board." This concern was framed in terms of medical social workers, not specifically AIDS social workers, but it is pertinent nonetheless. Another worker described stress arising from changes in hospital management which resulted in increased patient caseloads, as well as difficulties in working with administrators who did not share a social work perspective. Thus, the organizational instability which these subjects describe is related to problems stemming from either the AIDS Center, Social Work Department, or both of these.

As a result, study participants who saw stress as emanating from the organization were more likely to externalize their stress. Those who used organizational means of coping were more likely to consider leaving their job than those who relied on personal means. Ultimately, all participants believed the organization could do more to reduce their stress and to support them in their work. Yet, they also believed that they were personally responsible for monitoring and seeking assistance with unmanageable stress.

Training

Inadequate training was also seen as a low point for several social workers. Training identified as inadequate centered on particular patient populations and their specialized service needs. One such example came from a worker who had a caseload of patients who were active substance abusers. "If they're active abusers, it is frustrating because you can't deal with somebody whose other disease is blocking their ability to stick with the plan that they agreed to. It wasn't my plan; it was their plan. You know, this is what they wanted, but when they sober up, they change."

Some of these patient stressors, i.e., specialized needs related to death and dying work, drug abuse, non-compliance, could be mitigated by providing adequate training to address what subjects described as a gap in knowledge and/or skills. Training around these issues would be particularly relevant for AIDS social workers. In addition, training may also be relevant for working effectively within a team, dealing more productively with stress, and stress reduction techniques. Some patient populations constituted a significant stressor for many subjects. Adding the necessary training component could help increase feelings of competence and decrease some of this stress. In New York, many AIDS patients are from the inner city and have complex psychosocial issues which are further exacerbated by their AIDS diagnosis. Dealing with complex medical and psychosocial problems is itself stressful; drug use, poor compliance with treatment plans, continuing to practice unsafe sex, infection of entire families were all cited as additional stressors. Providing the social worker with tools or specialized skills to better deal with such problems and provide better patient care was seen as a need that could easily be addressed by the organization.

Balduck (1996) states,

> In order to promote compassionate, high-quality care for this population, the social work profession needs to continue to address the knowledge, attitudes, biases, and concerns of its members, for preventing stress and burnout among practitioners. Relevant in service training and social work education can help to minimize the resistance and difficulties in AIDS work (p.36).

Negative Patient Attributes

One social worker framed negative patient attributes as a non-compliance issue; it was particularly frustrating when patients did not seem to benefit from social work interventions and were seen as having an "abysmal social prognosis". Many participants voiced frustration with the same patients returning with the same problems, each time more of a drain because of their complex psychosocial issues. As stated aptly by one individual,

> I think it's hard to deal with patients who consistently fail, whether its drug treatment or referrals made in the community. They remain isolated and appear not to be able to use any of the resources that are available to help them. The frustration in dealing with that is hard sometimes.

Some of these clients seemed "entitled and narcissistic" which made compassion particularly difficult for one participant who was dealing with his/her own medical problems. This worker felt even more resentful as his/her own health declined from HIV disease.

The majority of study subjects discussed dealing with some type of patient resistance; including patients who rejected help or those who felt entitled to help. As one subject remarked, "I think sometimes it's really hard to deal with patients who consistently reject help or consistently fail at drug treatment, because there are resources available to them."

Unpredictable Deaths

Death and dying issues are, at times, seen as a stressor. Patients deteriorate physically and mentally, and their social workers often feel powerless when unable to do anything about it. One person stated, "The frustration [comes from] too many people's lives falling apart at the same time and feeling as though there was not enough time in the day to deal with all their needs." For some workers, the most difficult aspect was the unpredictability of death, likened by one person as a "roller coaster ride for too long with too many people. They were expected to die, but didn't." Not surprisingly, the stress from many of their patients dying seemed to have a cumulative effect. Especially difficult to deal with was the death of a patient who did not seem "sick enough". Conversely, it was difficult when patients were very ill and got better as they had already said goodbye. Multiple deaths in the same family were also reported as taking an emotional toll. It was interesting to note, however, their responses did not indicate a difference in stress between the deaths of adults or children. Patients are patients.

The Impact of Stress on Job Performance

Study participants all described stress as having some impact on their work performance; there was variability, however, in how great an impact it had. Most respondents said it affected their performance often, others, only some of the time. Several metaphors were used to describe the impact of stress and how they coped.

The Cycle of Fatigue and Rejuvenation

The metaphor one social worker used to describe stress and its impact on performance was a cyclical process of being energized and then depleted.

> When I am depleted, I feel less hopeful about the work I am doing for patients. I think I just do the minimum because that's all there is time to do. Sometimes it feels like I'm in a slump and I have to push myself to get out of it. During these times I sometimes withdraw from my patients.

Another said,

> I think this [process] is cyclical, feeling stressed and then bouncing back. I go through bursts of feeling energized and then I get burned-out.

This cycle of fatigue and energy metaphor seemed to resonate with many of the respondents.

> There are times I feel fatigued and sort of unable to deal with a lot more stress and sadness and so I withdraw, maybe not making the efforts I would make at other times when I am feeling more energized. At other times, the work is energizing and I am willing to do a lot of things, rather than a perfunctory job.

Some participants expressed the impact of stress as cyclical, but described it differently. One saw their work performance as a continuum of productivity. "Some days I'm on, and other days, I'm not. When I'm on, I go in, sit down, and really listen. If I'm not, I feel less in control and just check in." Another described feeling frozen by these stressors, and unable to function at work.

Participants also expressed uncertainty as to whether they would be able to deal long-term with their feelings of burnout. Feeling unable to cope with the stress was described as withdrawing from patients. One person called it "going through the motions" at work. Doing their jobs in a perfunctory way seemed directly tied to their level of stress and coping. As one subject put it, "I just go on trying to get the basics done (when I'm stressed) quickly and not spending time with patients." Whether they experienced an inability to listen to patients or to spend quality time with them, the impact of stress on their job created the narrow goal to just get through the day. "I go in and find out what the needs are, real quick write a note, and then onto the next one."

Participants also described a cumulative effect to their stress. As one worker explained, "If too many outside stressors are affecting you, one or two inner stressors (in the hospital, I mean) are working against what you're already dealing with, I think you can be unavailable for a patient emotionally, mentally, or physically. You could show that you are not interested in being there."

Mood Swings

Many social workers viewed the impact of stress as affecting their mood. Some expressed feelings of anger and frustration. Others reported becoming anxious in their response to job-related stressors. When their stress was externalized, they reported withdrawing from patients physically and/or emotionally. They described their moods as being internalized or externalized; internalized stress was self-directed, while externalized stress related to the organization or patients.

Internalized Stress

The internalization of stress seemed to happen in different ways, depending on the individual. These moods manifested themselves in feeling angry and frustrated, which subjects described as "bad moods," and were often self-directed. As described by one subject, "You begin to feel bad about yourself; you feel stupid and can't articulate your feelings when faced with stress." Another worker said, "Just like checking in with patients. Some social workers seemed to check out. My mind went blank. I went into my office. I said, let me sit down and rest, then I went home and slept all weekend." Another said, "I feel like I'm spinning out of control; like I can't function at all." And another, "You begin to question if you're going nuts; your self-esteem suffers." Other ways that stress was internalized was through a kind of self-sabotage, or acting out. Excessive drinking or overeating was reported as ways to deal with stress or to give themselves 'emotional nourishment'.

One participant described the stress reaction as an internalization process, referring to stressors experienced from within the organization. Even though some stressors originated outside of the workplace, this affected their mood at work. When this happened, the amount of stress experienced was seen as "putting me over the edge." Still others described the stress as being external to themselves, as the next section will illustrate.

Externalized Stress

Those who saw stress as emanating from things in the organization were less likely to internalize the stress. Yet, stress was sometimes seen as being acted out in the care of patients. The way some social workers reacted to stress was to withdraw from patients. "It gets harder and harder to come to work every day." Yet, this same respondent remarked that what keeps her coming back to work were the patients. For most AIDS social workers, patient care provides job satisfaction.

> There are some days when I go home and I don't feel satisfied and think it's been those days when I've had twenty patients and I've had to run here and there and everywhere. I think the days when I feel more satisfied are the days when I had been able to spend time with patients and maybe set them in the right direction in terms of a benefit or so I measure whether it's been a good day or satisfying as I go from here to home.

Participants who saw stress as related to the organization, rather to patients, were more likely to be male, were less likely to internalize the stress, and dealt with the stress by withdrawing from patients.

Gender Differences

Only two social workers, both male, said stress had no impact on their job performance. One related this to his work as a discharge planner.

> With every patient that I'm discharging from the hospital, I know I've arranged the discharge plan. There is a lot of satisfaction in knowing where a person's going, that they're linked to services, that they are going to be taken care of when they leave the hospital, which is a surprise because discharge planning has sort of a negative connotation to it. I was afraid of it, but I went for it because I wanted hospital experience and I'm finding that actually it's pretty fulfilling.

The aspect of his job that was concrete and helpful (i.e., discharge planning) seemed to enhance personal feelings of accomplishment and job satisfaction.

Responses were fairly consistent for the majority of social workers who reported they were largely able to cope with AIDS work-related stressors. However, all participants admitted to feeling consistently stressed. Gender seemed to be a factor in responses about the ability to cope. Men seemed more reluctant than women to say they were unable to cope with their stress. One female respondent admitted, "I cry fairly often at work. Occasionally, I get hysterical when I attend a patient's funeral." A few respondents felt they were sometimes unable to cope with work stress, but each described it differently. One said, "About once I month I feel like I can't cope." Another explained it as a cumulative process: "Well, it's compartmental, but it seems to be happening more frequently."

A few respondents appeared confused by the question when asked whether they were ever unable to cope with stress. They said they push themselves to keep going or go to work regardless of their feelings. Both of these respondents were men. One stated, "I have a strong capacity to keep going no matter what; but that's not necessarily coping." The other said, "It's not about coping. I've mandated myself to come to work every day and do what I need to do." He went on to say that, even if he has trouble coping, he does not want to show it at work. Coping was not always seen by participants as effective. At times it was viewed as "showing up and just going through the motions."

In contrast, some study subjects were very clear about always being able to cope. As one put it, "I can say honestly that I don't think I've ever felt unable to cope. I've felt stressed, but it doesn't send me over the edge in terms of I'm leaving or I'm getting out of here. I've never reached that point." Others vacillated in their ability to cope by saying, "I think momentarily I will be unable to cope, but I'm able to gather myself together and use the resources around me for the most part."

Taking time off, seeking staff support, or seeking private psychotherapy were mentioned as helpful responses to mounting stress levels which participants made prior to being unable to cope.

Conclusion

Organizational stressors were, overall, found to be the low point in AIDS social workers' jobs and, in fact, were viewed as contributing significantly to some workers' decision to leave the field. Among the organizational stressors reported to be most difficult and disruptive to good patient care and worker job satisfaction were changes in the health care system, facility reorganizations, increased managed care which reduces professionals' choices and increases patient stress, and the threat of potential staff layoffs. On a personal, day-to-day level, lack of flexibility and lack of job autonomy were also viewed as particularly stressful.

All of these organizational stressors were experienced as adding pressure to an already stressful job, and, in fact were viewed as more difficult to handle than those inherent in AIDS patient care. Moreover, while some of these stressors were not within the control of management, others were -- and were cited as causing the most distress. Among them were a lack of social support, collegiality, formal support groups, or memorial services, as well as supervisors who were seen as unsympathetic to staff pressures nor supportive of staff requests, particularly when these might alter slightly usual routines, schedules, or practices.

Indeed, actual patient care was also reported by some as a "low point", particularly the inevitable "roller coaster ride" involved in working with AIDS patients. The unpredictability of the disease and its day-to-day progress were the source of extreme distress for some respondents. Patients who appeared to be doing well medically might die, or conversely, those in the end stages of the disease would experience a remission. This lack of predictability and its cumulative effect with multiple patients was viewed as particularly difficult. For this reason, organizational stressors may be perceived by workers as all the more frustrating, given the expectation that management "should" provide an environment supportive of both staff and patients.

Whatever their expectations or reasons for entering the field of AIDS work, because of the nature of their jobs, workers require numerous formal and informal support structures in the work environment in order to remain replenished. Significantly, the work environment itself was not reported as helpful in sustaining them, nor, sadly, were their relationships with others on the multidisciplinary team.

Despite the difficulties and disappointments created or exacerbated by the work environment, study respondents reported that the major factor sustaining them in the work is the work itself. The rewards they experience in working directly with AIDS patients are the subject of Chapter VI.

CHAPTER VI

THE REWARDS OF AIDS WORK: WORKING WITH PATIENTS AND FAMILIES

> You look into each other's eyes and you share soul-to-soul and that's what sustains me most and so I try to remember that as much as I can.
>
> The only thing that helped me to get back was the poignant and satisfying moments with patients.
>
> Quotes from AIDS social workers

Introduction

The intensity of work with patients and families was viewed as one of the main factors which replenished AIDS social workers who participated in this study. Whether it was helping patients die with dignity or maintaining their quality of life for as long as possible, study participants believed they made a difference. This chapter will present the findings on how their work with AIDS patients and families replenished them.

Conceptual Framework

Strug, Grube, and Beckerman (2002) posed an important question regarding recruitment and retention of HIV/AIDS social workers. "Do the rewards of HIV/AIDS social workers remain sufficiently satisfying to attract new practitioners to the field and prevent practitioners from leaving, given the enormity of the challenges workers will face in the next stage of the epidemic?" (p. 14).

Many researchers have written about the relationship between recognition, rewards, and burnout (Bennett, 1996; Offerman, 2002; Siegrist, 1996). Siegrist proposed an "effort-reward imbalance model", which is based on a reciprocal balance of intrinsic and extrinsic efforts and rewards (p. 351). Work efforts can be extrinsic, such as work pressure, or intrinsic such as coping patterns. Extrinsic rewards include job status or money, while intrinsic rewards might include increased feelings of self-esteem. In this model, the most stressful imbalance would be a job requiring high cost (effort) with low gain (reward). Therefore, creating a balance between the high effort jobs, such as AIDS work, requires understanding what AIDS social workers experience as the positive aspects, or high gains, of their work.

The present study sought to identify the rewards of HIV/AIDS social workers which balance the stressors and potential for burnout. According to Offerman (2002) who studied nurses working with HIV/AIDS patients, the reward is in patient care itself.

> Emotional exhaustion is a hazard of frequent and intense personal interactions for human service professionals... [however] nurses who spent more time with paperwork were more stressed than those providing direct patient care (p. 69).

She reports further that, "nurses, who have more patients in their caseload and, likewise, those who spend less time in direct care, may have less time to spend with each individual patient" (p. 74). In another study, Gimbel, Lehrman, Strosberg, Ziac, Freedman, Svicki, and Tackley (2002) "found clear differences between predictors of job satisfaction for employees who interact directly with AIDS clients compared with those often removed from the 'front lines'" (p. 51).

Bennett (1996) reported on the relationship found between recognition, rewards, and burnout. The author describes these in terms of HIV care, stating gratitude from clients is considered a major reward for caregivers. Patient appreciation, in conjunction with feeling their work is making a difference, were found to be considerable rewards for HIV/AID social workers.

In her work on resilience, Kobasa (1979) described characteristics constituting psychological hardiness, which includes commitment, control, and challenge. Commitment was described as having a purpose or meaning to your work as well as an active involvement in life events. Because a cure is not yet possible in AIDS work, social workers find other ways to contribute which are of value to patients and to themselves as well. Price and Murphy (1984) found that feelings of making a difference in peoples' lives can empower staff, regardless of the lack of a cure for AIDS.

Helping patients with psychosocial issues, including a "good death", has been described by AIDS health care workers (Bennett, 1995). As one nurse said, "You are helping them (patients) die with dignity and feeling you're doing something worthwhile" (p. 97). Even though end-stage care is stressful, it is viewed as an emotional growth experience by workers. The positive aspects of the work are intrinsically tied to their strong emotional bonds to patients and families. Multiple hospitalizations and long timeframes of chronic care create these bonds. "Emotional bonds, both positive and negative investments of energy and interest, hopes, and expectations are among the factors that give meaning and significance to a loss" (p. 85). In addition, "The sense of achievement and skill attained (in AIDS work) is extremely significant for social workers in avoiding stress, a sense of burden, and burnout, and in attaining satisfaction" (Davidson, 1995, p. 67).

In fact, the bonds health care professionals form is sometimes described as "family". Discussing this experience, one health care worker said, "When they develop AIDS, all they experience is rejection until they encounter us, and we become the support for them. We become the family for them, which have never happened to me working in oncology (Bennett, p. 89). For AIDS patients, stigma, miscommunication, and family conflict due to factors such as alternate lifestyles or drug use frequently can lead to isolation and rejection. Health care workers who provide hope and empathy over an extended period of time help to heal these emotional wounds. Also, at the time of the patient's death, it helped patients and workers to feel their grief is legitimized or socially sanctioned. Thus, although the emotional drain from AIDS work is great, the literature shows the emotional intensity of patient relationships provides sufficient reward and satisfaction to make this work worthwhile.

Intensity of Relationships

High Points in AIDS Work

The primary reason given by all study participants as to how they were able to continue doing this stressful work was their satisfaction in working with patients and families. Even though there was unanimous agreement that working with AIDS patients was sustaining, there was some variation in how the rewards were defined. For some, the intensity of the work and the connection made with patients and families were described as the high points. The intensity of AIDS work seemed to allow a level of closeness between patient and caregiver which was different from that found with other illnesses. As one person stated...

> The word 'AIDS' has a mark to it. There is a huge label attached to it. It's the intensity of the illness and the tragedy of it. I think a major part of it is being drawn to life and death issues and all the special things involved. The fact that an AIDS patient needs someone who understands everything from the psychosocial to the physical implications of the disease, discrimination, stigma... I mean, it's different than other diseases.

In fact, one person defined the closeness of their relationship as "family." "Patients refer to me as family. They do this regardless of where I came from or what the color of my skin is."

These intense, close relationships were described as helping to contain the stressful part of AIDS work. AIDS social workers saw it as a privilege to work with this population. "I am grateful to work with patients. It's like a privilege to me. I really like working with patients." Feeling the closeness to their patients was evident in many of the responses. One worker eloquently summarized the feelings, "You look into each others eyes and you share 'soul-to-soul' and that's what sustains me the most and so I try to remember that as much as I can." Watching patients deal with the complications of AIDS can also be emotionally draining, yet rewarding. As one social worker said, "Patients are our inspiration. They are living as humanly as they can."

One respondent found rewards in working with patients in the late stages of AIDS, "I think that the really ill patient is where I find the most satisfaction. I think it's very difficult, but ultimately the personal rewards outweigh it." Others found working with people with a life-threatening illness was inspirational, especially in how they dealt with their disease. "Watching the emotional growth and strides people make is (in itself), rewarding to me."

Although patients were generally referred to as a group, it was not uncommon for respondents to mention a few patients who seemed to stand out for them from the rest. I refer to them as "the special patient".

The Special Patient

Several social workers acknowledged a particular fondness for a patient or patients, the relationship "sticking with you" more than others. A few commented on the closeness of that patient or how their memory stayed with them even after their death. The patient(s) were often seen as somehow different, in a "special" way.

An explanation given by one respondent was,

> I had a patient. . . It's funny . . .patients that you had years ago stick with you more than some of your current patients. There was a woman who had triplets and they were healthy. I thought she was crazy when she did this (all could have been born infected) . . .my high point was when all her kids turned out negative(seroreverted or back to HIV negative). That was exciting. I have their pictures on my desk. They are going to be healthy and that's pretty cool.

In describing the death of a special patient, one social worker said, "Recently one of my long-term, very intensely close patients died and that was very, very difficult." She described this patient as having been special to her and feeling conflicted in helping them die, while having a lot of difficulty letting go.

Many of the social workers who discussed having a special patient memorialized them through pictures, stories, or by staying in contact with their family. One worker, during the interview for this study, pointed to her "wall of patients". She pointed out three patients as being special, who had touched her life in some manner. She continued by remarking, "There was one patient I worked with for seven years. They educated me about the human spirit." It was not unusual to have AIDS social workers talk about the lessons learned from patients or how they had touched them in some way, even long after their death.

Interestingly, when a "special" patient died the event could be defined as both a high point and low point for the same social worker. As one social worker described it,

> I worked very closely with one patient and then as his health declined, I was helping the family prepare for his death and their own feelings of bereavement. It was a very bizarre high point. I found myself not believing that I was the one standing in the room at the moment he died and that the family leaned on me for support. And so I think just finding that inner strength to deal with his death and be there for the family was the most amazing experience, so far. Unfortunately, this patient passed away, which is one of the lowest points I've experienced.

Maintaining Quality of Life

The other aspect of patient care that was reported as sustaining for AIDS social workers was helping patients maintain their quality of life. Maximizing how patients lived was very important. As one person said,

> I think its very rewarding to see people doing well, to be a witness to people's accomplishments and their successes with coping with the illness, whether it be just physically improving, or sometimes the emotional strides that people have made, the acceptance of themselves, and the personal growth they experience being able to find meaning in their lives. This is really rewarding.

Social workers believe they have a role in helping patients to live their lives fully. This is especially true in the care of AIDS patients, given the availability of life-sustaining medication treatment regimens. As patients live longer, social workers reported the impact of their care could be felt, as patients encountered ongoing complications from the illness, as well as the many psychosocial problems which accompany AIDS. This "changing face of AIDS" was acknowledged by respondents and experienced as a focus which sustained or replenished them in their work. Patients were described as having a new lease on life with the emergence of chronic case management that allowed patients to live longer and healthier lives. Social workers saw themselves as integral players in providing the support patients needed to cope with the psychosocial sequelae of AIDS-related diseases.

Study respondents also reported high points from helping patients reunite with their families when there had been separations due to geographic location, lack of acceptance of alternative life styles, or patients needing care with the progression of their illness. Respondents found it very rewarding, especially when such a reunion was a mutually rewarding experience for patients and families. Even for those families who did not need reuniting, opening lines of communication between family members was fruitful. “I really like the feeling I get when I help patients and families to communicate and eventually to connect with each other.”

Even when a patient died, it was not uncommon for respondents to continue to work with other family members who have been affected by or infected with AIDS. This situation may be experienced as a stressor, with multiple deaths in one family, or it can be fulfilling with their long-term family relationships.

> I have one particular patient I've worked with since I've been here. Her son died three years ago. She's still my patient. She's had a difficult life. I've been able to help her with these difficult times, including the death of her son. I've seen her grow and make sense out of the depressive things in her life.

In order to feel AIDS work was sustaining, respondents said it was important to have enough time and support to do their jobs effectively. They often described a lack of time, lack of support, or bureaucratic barriers as having the most impact on the stressors inherent in working with AIDS patients. One social worker acknowledged, "The days I feel most satisfied are the days when I have been able to spend enough time with patients and maybe set them in the right direction." Many said that the longer patients lived, the more time was necessary by social workers to manage their care. Increasingly, to be fulfilling, the job required time, support, and direct patient care. More than one respondent stated "Chronic care management involved with people with AIDS requires more coordination of care over time and throughout an often complicated course of illness." Therefore, depending on the organization and amount of support available to AIDS social workers, AIDS work was experienced as very rewarding, or alternatively, very stressful, important distinction organizations must understand in order to attract and retain social workers.

Helping Patients Die with Dignity

Several study participants defined their work as helping patients die a good death, meaning, helping them to die with dignity. This they considered the high point of AIDS work. The dying process, although a sad time for patients, families, and staff, was frequently viewed as a rewarding experience. One worker said, "Patients coming to grips with their own mortality in a peaceful way, or patients who can really live in the face of illness and death, can be very satisfying to work with as a social worker." Still another responded, "The really ill, dying patients are where I find the most satisfaction."

The very fact that AIDS is an incurable disease and death may be the outcome helps to prepare social workers for this challenge. Even though the pain and sadness were seen as a normal part of this process, participants still felt this was a high point in their overall job satisfaction. The appreciation they received from patients and families facing death and dying issues coexists with the sadness. As one person stated,

> I guess I would have to say that the high points are generally the appreciation I get from patients and that's true even in the worst circumstances. For example, when a family's child died, I was with them throughout that, but you know at that point they were thanking me for all the help I gave. It was an extraordinarily sad situation, but it gave me the feeling that it was somehow worthwhile, despite the pain.

Although there was acknowledgement of the pain and sadness, working with patients in the later stages of AIDS was seen as important, fulfilling, work. One social worker said, "What I am most proud of is helping patients and their families accept death as a natural process."

Whether the goal was described as helping patients die with dignity, accept impending death, or take control over when "enough is enough", there was a belief by respondents they could help patients achieve the goal. Good communication and a continuity of care model were viewed as two important aspects of successful care. Communication with patients and families, as well as with AIDS team members, was seen as essential to social workers. Effective communication included an ability to talk openly and honestly about the patient and their condition, including when quality of life was no longer an option for the patient. Communication was seen as central to developing a realistic treatment plan, known to and agreed upon by the patient and providers. Similarly, when there were disagreements, respondents believed good communication between patients, families and caregivers serves as a catalyst to reaching consensus.

Respondents also stated the continuity of care model, in which the social worker remains with patients whether they are in-patients or out-patients, was the best model of care. An expectation with this model is that social workers would spend a significant amount of time at the bedside of a dying patient. "I expected to touch people's lives at a vulnerable time and although terminal illness is a part of that work, there was also satisfaction in forming long-term relationships with patients." While recognizing this was not easy work, it nonetheless appeals to workers, who feel the sadness and cumulative loss of patients dying are outweighed by feelings of doing work which is meaningful and appreciated.

Another rewarding part of their jobs was using their skills to help patients face death.

> For a long time I didn't realize what was so special about my skills. I sort of felt like I go in a room and talk to people. . . Sometimes I lose what is special. Yet working in AIDS, in a difficult moment I sit with a family with an impending death in front of them that is coming closer, I am able to let the family break down and then bring them back again to focus on what we need to get done. It's extremely fulfilling to me to be comfortable enough to sit with feelings of a person who has AIDS and what they are going through.

Overall, this study found it is the death and dying work which, although challenging, was described as the best part of the job. As one person aptly put it,

> There are times when everyone is working aggressively to help the patient keep going (regardless of the patient's wishes). I help the patient and their loved ones to recognize this is the end stage of the illness and have them communicate more honestly with each other to know where their line is (when to stop treatment) and really hear what the patient is saying. They need to be able to let go and help the doctors who want to save him to hear the patient's wishes. To do that kind of work where you go into a room and the patient looks me in the eyes and says," You know what I'm talking about". That's what this work is all about; in fact, it's the best part of the job.

There is also a feeling of being appreciated by patients and families that plays a role in this process.

Respect and Appreciation

Several subjects identified the respect and appreciation they receive from patients and families as the factor that sustains them in this challenging work. Most said they expected AIDS work to be challenging, even difficult, at times, but expected it would also provide feelings of personal satisfaction. Some described the appreciation they got from patients as sustaining, while others called it one of the most rewarding parts of their jobs.

Whether helping patients to maximize their lives while living with AIDS, or to cope with the terminal stage of their illness, study participants felt their role was sustaining, and even rewarding. As one social worker put it, "Although there is still no cure, there are many medications available making it more of a chronic illness with people living longer . . . patients that would have died now [are] having a new lease on life."

It was clear in these interviews that helping patients maintain a good quality of life was very important to participants and was seen as a high point in their jobs. However, they found it just as important to help patients with the death and dying issues related to having an incurable disease.

Making a Difference

The desire to have made a difference in helping patients maintain their quality of life or deal with death and dying was communicated by study subjects in several ways, but whether helping patients live or die, they found personal satisfaction in all aspects of their work. As one person said, "Patients depend on me. They trust me with their lives and deaths." Having open communication with patients and families and supporting them throughout the course of their illness were at the core of these mutually supportive relationships. Understanding the needs of patients and being able to help meet their needs was seen as very fulfilling. The vulnerability of patients at a very significant time in their lives added to caregivers' satisfaction. "A high point can be every day. For example, when I walk into a room and see a frightened patient sitting on a bed, I feel like I've been of value to them; you know, made a contribution, I've made a difference."

There is a richness described in the quality of relationships that develops between patients and social workers. Study subjects reported the emotional growth and personal strides patients make is rewarding. Being allowed into their lives during these difficult circumstances was also seen as sustaining, and seemed to explain in part why some choose to stay in AIDS work. One participant summed up these feelings with, "Helping patients is what it's all about." One said her high point was "bearing witness to the kind of love and support that AIDS inspires in a community or family." Regardless of the stage of illness, participants reported being able to find personal satisfaction in making a difference.

It was clear from these interviews, feeling close to patients and believing you have made some difference in the quality of life, or imminent death, was very important to participants' overall job satisfaction. Rather than focus on the illness and the possibility of death, patients fought to live. This sense of hopefulness and courage exhibited by patients with HIV/ADS was an inspiration for participants. According to Shernoff (1994), hope is an essential element which helps patients cope with HIV/AIDS. The two components necessary in remaining hopeful are a positive focus and an orientation toward the future. Witnessing their courage and will to live, even in the most extreme or seemingly hopeless circumstances, were life-altering and a form of replenishment for most of the AIDS social workers in this study.

Conclusion

The most significant finding of this study with regard to the rewards social workers find in doing AIDS work was that it is the work itself which is most satisfying. Further, while challenging and stressful, the work is also a source of worker replenishment.

One might wonder how the challenge can also be the reward, but it was the one-to-one, longer-term relationship with patients and their significant others which were clearly and repeatedly cited by study respondents as the reward for doing this challenging and demanding work. Whether helping patients to die with dignity or to maintain quality of life throughout the course of their illness, social workers in this study reported this as the best part of working with AIDS patients.

The specificity of this response is important: direct patient care was the activity which the majority of workers reported as most rewarding. Similarly, longer term care that enabled workers to form meaningful relationships with patients and their families were seen as the most rewarding care assignment. Of particular importance in continuity of care was the closeness required to help patients accept their own mortality and to regain a measure of control by defining what, to them, would be "dying a good death".

Perhaps as a result of their special type of caregiving, study respondents reported an interesting aspect of their work, designation of "special patients". Each social worker discussed a patient or patients who had become "special" to them. Even when the patient had died, they were somehow memorialized in pictures and stories. Respondents often could not articulate what made a particular patient special, or how this heightened feeling may have affected their work with them. Exploration of the "special patient" phenomenon would be an interesting area for further research.

Without question, AIDS social workers were found to require both the time to spend in direct patient care and a supportive, flexible environment in which to help deliver it. Perhaps for these reasons, study respondents expressed the greatest frustration with real or threatened organizational disruptions to the continuity of care for their patients. Remediation of such disruptions would improve quality of care while creating a necessary buffer to the stressors of the disease itself, regardless of the care setting.

Thus, if health care organizations wish to recruit, attract, and retain experienced AIDS social workers, they must also invest in those environmental elements which contribute to workers' replenishment, i.e., protection of caregivers' time, autonomy, and patient relationships, for these are the elements which both drive staff and replenish them.

While AIDS workers "know" they must take care of themselves as well as their patients, as Bennett (1995, p. 92) said, "Health care workers in general are better at giving than receiving (support)." This study showed clearly that, in AIDS work, they must do both. Chapter VII will present the study findings on how participants cope with the losses of AIDS work and replenish themselves in order to continue it.

CHAPTER VII

SELF-CARE: COPING WITH THE STRESS OF AIDS WORK

> I think momentarily I will be unable to cope, but I'm still able to gather myself together and use the resources around me to cope.
> Quote from an AIDS social worker

Introduction

AIDS social workers who participated in this study were able to articulate the stressors involved in their work, as well as to describe the types of self-care they use to buffer their stress. In fact, the responses from those interviewed made it clear they take primary responsibility for avoiding burnout, rather than expecting their supervisor or organization to provide such supports. This chapter presents an overview of the literature on what social workers do to cope and replenish themselves, as well as the techniques described by participants in this research.

Conceptual Framework

Sotile and Sotile (2002) state, "80% of published studies have demonstrated a positive relationship between religious commitment and health" (p. 83). These researchers found people with active spiritual lives also report having lower levels of depression and anxiety compared to those who rely less on their spiritual beliefs/faith. As reported by Horsman and Sheeran (1998) "Spiritual beliefs/religion were cited by 20% of health care workers as factors that contribute to their ability to cope with the stress of caring for AIDS patients". (p. 1538). Skovholt (2001) found, "For some practitioners, formal religion offers a rich structure of beliefs that provide meaning and purpose and helps them confront mortality with answers and assurances" (p. 125). Such findings seem especially relevant in AIDS work, where practitioners are confronted with human suffering and death. Skovholt concluded, "The reality of death is a major motivation in the human quest for a spiritual religious life" (p. 161).

Caregivers for people with AIDS often must deal with existential questions posed to them: What is the meaning of life? Why did God choose me? What is God's plan for me? Such questions are not uncommon in social work which involves caring for patients with a terminal illness. Workers' own religious/spiritual beliefs play a role in how they experience their work and whether it is also viewed as a form of replenishment. According to respondents, religion and spirituality played a key role for some staff outside of work, but in the work environment itself, others found tremendous support from supervisors.

Supervision of AIDS social workers plays a crucial role in staff replenishment and in helping to mitigate job-related stress. According to Itzhaky and Atzman (1999), "The purpose of supervision in social work is to help the worker function well, to reduce sources of stress and pressure, and help him/her cope with those [stressors] that cannot be eliminated" (p. 63). Ivancevich & Matteson (1983) found staff needs to feel their supervisor can be a buffer between them and the larger organization. They defined such supervisory support as "going to bat for them".

Leiter and Maslach (1988) addressed the differences between those described as pleasant supervisors versus those seen as unpleasant supervisors. The impact of stress on staff varied, based on this perceived difference. Workers supervised by the "pleasant" supervisor experienced a sense of more personal accomplishment, whereas those supervised by "unpleasant" supervisors expressed more feelings of emotional exhaustion. Thus, the person in the role of supervisor can enhance work experiences and buffer stress, or they can undermine staff and add to the emotional burden of an already stressful job.

According to Kadushin (1992), the supervisor plays several roles: educator, administrator, and supporter. Assisting in staff training and skill building, as well as helping them resolve conflicts are important tools to help staff manage stress. Key characteristics found to be attached to "successful supervision" include: respect, trust, and open communication around grief and loss.

Research also shows the educational role in supervision helps workers manage stress. Itzhaky & Atzmon (1999) reported, "It is important to teach the worker to identify signs of their own anger, vulnerability, stress, and burnout in the course of caring for patients and teach them to recognize their own power, inner resources, and influence on stress and its prevention" (p. 70). The supervisor may, in fact, be a social support to their staff, as are co-workers and care team members.

Social support according to Willis & Filer (2001) can be "broadly defined as resources and interactions provided by others that may be useful for helping a person cope with a problem" (p. 209). Social support in a work environment is generally provided by peers, teams, or supervisors, and may be informal support, or organizationally sanctioned group support. Teams working together in HIV/AIDS experience many similarities in their work and can therefore come together as groups to deal with job stressors, i.e., grief work facilitated through group support. Catherall (1995) reported a synergy from group support, which is lacking in individual support.

Itzaky & Atzmon (1999) assert, "Group support enables reciprocity and reduces the distance among workers, allowing them to share experiences that arouse stress and those that bring satisfaction creating a mutual support system and reduce stress" (p.70).

The care team can also be a source of stress reduction. According to Brown and Stermock (1999), a well-functioning team helps buffer the stress experienced by AIDS workers. Similarly, Guzzo and Shea (1992) found "pro-active teamwork... to be one of the most powerful organizational interventions to improve mental health in the workplace" (p. xvii).

Certain characteristics were identified as helping to moderate stress in high stress trauma work. According to Flannery (1990) the following components are seen as effective stress buffers: 1) emotional support; 2) information; 3) social companionship i.e., a sense of workplace community; and 4) instrumental support i.e., tangible help. (Catherall, 1995, p.82). Characteristics of effective institutional support allow for ventilation, sharing of cases, and providing coverage for time off, as well as listening and understanding. Catherall (1995) found empathetic attunement to be a characteristic of effective social support and described it as listening with an empathetic ear (Catherall). In the absence of institutional support, bonds which provide social support can emerge spontaneously.

Wade and Simon (1993) described informal supportive relationships formed to buffer high stress levels in a pairing of ten AIDS health care professionals who formed "survival bonds". Characteristics of the support provided in these relationships included respect and trust, ventilation, shared decision-making and emotional support. Although such bonds can emerge spontaneously, as they did in the Wade and Simon study, the authors asserted there is still a need for formalized staff support. Organizations and staff share the responsibility for understanding and responding to work stress. Individuals can identify coping techniques to meet their own needs; organizations can provide additional mechanisms for support through formal structures.

Although social support in the workplace is essential, there also needs to be some separation between work and home. In fact, setting boundaries for oneself to maintain a healthy balance between home and work life helps to avoid emotional exhaustion and burnout.

According to Skovholt (2001) personal balance rests on four dimensions: 1) physical; 2) intellectual; 3) emotional/social; and 4) spiritual (p. 162). Time management skills are also necessary to stay balanced. Setting priorities and scheduling activities which nurture the four dimensions helps to maintain a healthy balance between life and work.

Self-monitoring is also a part of being able to sustain balance. This includes a process of self-regulation which is necessary to keep stress and overwork from becoming regular events. The work environment can support this self-regulation as well. "One of the guiding principles of preventive stress management is that the individual and organization are responsible for health and well-being" (Nelson, Quick, & Simmons, 2001, p. 358). Allowing staff time off and flexible work schedules helps them to feel more in control and autonomous. Management can also reinforce and model the desired behaviors of their staff as a way to avert burnout.

Another form of self-care includes "therapy for the therapist" (Skovholt, 2001, p. 148). Stressful work, combined with the numerous losses of patients in AIDS work, can lead to cumulative emotional distress. Personal therapy is useful to manage such stress.

Also, social workers must deal with their own counter transference issues related to HIV/AIDS work. Social workers who are HIV positive or have been diagnosed with AIDS must deal with their own personal life crisis. This can increase the chance of making mistakes or clouding one's clinical judgment. Therapy allows one to deal with their own feelings and experiences, hence freeing them up to be more self-aware and emotionally available for their work with patients. (Schernoff, 1994).

According to the findings in this study, those who had previously been in therapy may return when needed. Others enter therapy when psychological distress is evident. An overlap was found between therapy and clinical supervision. Although not the same, individuals used supervisors to vent feelings and deal with loss because they considered this a "safe" place to do so. When the supervisory relationship was reportedly unsafe or the relationship strained, staff were more likely to seek out their own therapy. A combination of therapy and a supportive supervisor enables social workers to express their own feelings, which can buffer the chronic effects of stress.

Skovholt (2001) also found hobbies to be a common way AIDS social workers take care of themselves; interests outside (of work) were described as forms of renewal. The use of hobbies in the self-care process was called "positive, significant distractions" (p. 157). Those that involve physical exertion were seen also as a form of exercise, i.e., gardening.

Research supports the benefits of exercise on psychological well-being (Skovholt, 2001). "The vast majority of studies examining the role of exercise on psychological well-being and mood, support the notion that exercise will improve well-being and mood states such as anxiety, stress, depression, tension, and fatigue"(p. 154). Skovholt found exercise is used as a way to reduce stress and feel replenished. In fact, some individuals described a compulsivity related to their exercise rituals. Others who had used exercise to reduce stress replaced it with alternative therapies for replenishment when limited by time or health.

Henderson (2002) reported health care professionals use alternative therapies for their own use and with their patients. Increasingly, alternative therapies such as relaxation techniques, yoga, and acupuncture have become a part of the traditional health care system to reduce stress and aid in coping. According to a survey of social workers, 321 who responded (out of 1,000) reported using alternative therapies as a part of their ongoing practice. Social workers use alternative therapies to help their patients maximize their physical and emotional health. Belief in the mind-body connection creates openness to non-traditional methods. "Alternative techniques and practices are guided by a holistic perspective or holistic theory of health" (Henderson, p. 57).

In a study of what psychotherapists used as their number-one coping strategy to maintain their well-being (Fry & Salameh), 82% of the sample said it was by maintaining a sense of humor. The use of humor in a chronic stress environment was described as a way to reduce stress, build relationships between providers and teams, and help to diffuse difficult situations. Laughing, joke telling, and a sense of humor have been identified as coping strategies having both short and long-term benefits. Another study (Reinhold, 1977), found the use of humor can be an antidote to reduce burnout in a toxic, stressful work environment. The use of humor by leadership, or acceptance of its use by staff, gives permission to the group to do the same. "Humor can bring teams together and help staff cope" (p. 42).

Self-Care Coping Techniques

The Role of Spirituality and Religion

The AIDS social workers interviewed for this research study spoke of the role of organized religion and/or spirituality as an important factor in their ability to cope with the stress of the job over time. For some, religion had been an integral part of their lives prior to working with AIDS patients, but it was also described as a coping mechanism in their work. As one worker put it, "I trust in the Lord. My church activities are important to me." Another social worker said, "I'm a Dominican sister, so I think that's probably how I have lasted longer than some people have . . . it's like *staying power*." A third social worker said that, "Trusting in the Lord has helped me cope." She elaborated, "I would probably say at home I bring in my own prayer life" in regards to dealing with her work in AIDS. Additionally, participants discussed church life and related activities as sources of social support which also helped them cope.

The type of faith which study subjects found to be helpful in coping with stress did not always involve organized religion. Some participants described their beliefs as a faith in a higher being; still others used the term "spirituality" as a source of coping. One worker replied, "I'm getting closer to God, but not in an organized religion way." As she put it, "I believe spirituality helps a lot" when referring to how she continues to perform on her job. For several participants, religion/spirituality was seen as vital aspects of their work in AIDS and of their ability to maintain a manageable stress level. "I have a daily spiritual practice. I get up early in the morning to have quiet time to read and pray. Throughout the day I try to remember . . . not to get too caught up in the drama—but to make connections with my inner self." In a few cases, there was a meditative quality to their beliefs.

Even though some workers were already practicing some form of religion/spirituality, a few respondents discussed more actively expressing their religious beliefs as a result of their work, i.e., "I joined a prayer group. I believe spirituality helps." Some found support from their spiritual community and its related activities. For some, their practice of spirituality was an internal process involving prayer and/or connecting with a higher being, while others described it as an external model of support and comfort through attending church services and activities. Both groups found great comfort in their faith and clearly defined it as a main support in coping. Social workers described their spirituality and religious life as a type of nourishment for the soul. Like those who self-identified as finding support through the LGBT community, these respondents found a feeling of community affiliation and support through religion and spirituality. Like religion, social support is important in buffering stress for health care workers.

Social Support

A key coping mechanism noted by all respondents was social support. Two groups were described as sources of social support: 1) family/friends 2) peer/team support. Similarities between the two sources emphasized their importance for ventilation of feelings and receiving emotional comfort to help them cope with the stress of their jobs.

Family and Friend Support

Many study subjects said they depended on family and friends to help decrease stress. One said, "I found myself re-energizing friendships and paying more attention to the home-front." Another worker said talking about work at home made them more aware of the values of their work.

> If I talk to someone who doesn't work with people a lot of times they remind you of how wonderful it is to be a social worker. It reminds you of the special quality it takes to be able to do the work. That, for me, reduces stress because I feel really good about that. They don't really quite identify what it's like to be in a room with a family when their parent is passing, you know, is about to die.

Some had friends who were in the field and understood better what their work was like. "I have relationships with social workers from work who are close personal friends and I see outside (of work)." There was a feeling that, although they were supportive, they were stressed themselves.

Family relationships also provided support, and allowed workers a way to remove themselves from their work.

> I get e-mails at work from my nieces and nephews and we e-mail back and forth, so it kind of takes you out of here. It takes you away. Kids always do that. I have a wonderful family. I am able to talk about things that happened during the day and they're interested.

One respondent summarized the benefits of social support, "I rely on people personally and professionally to vent, share ideas, and get support". Whether it was social support provided by families or friends, or co-workers, respondents needed a great deal of emotional support to help them stay replenished.

Peer Support

AIDS team members and supervisors were also identified as providing needed support. "Our supervisor is a part of our team; they set the tone for the profession and the respect we get." Getting perspective from team members is seen as an essential aspect of coping. "After I had an incident with a mother, I went to talk to the psychiatrist and was able to vent and get some perspective. I think having the support of other team members is hugely important (in coping)."

Another person described their relationship with their supervisor as a support. "My supervisor is a magnificent support system, including being a role model, teacher, and friend—all-in-one." Social support from peers was seen as very valuable; in fact, it was described more as a form of bonding, describing a technique of survival which helped them cope and decreased the stressors of this difficult work.

Bonding

Bonding, a type of social support which occurred between staff, was seen as very important in coping with AIDS-related stressors. As stated by one individual,

> I feel like it's the front-line social workers— we've bonded. It's almost like an old-fashioned wagon train, you know, you pulled your wagon around to defend your turf. But even in pulling the wagons, you're all linked together. There's an entire link between the social workers, themselves, like in our group of helping each other cope.

This wagon train example projected an "us-against-them" metaphor, which is a common theme in workers' descriptions, as if their actual survival depended on others in the AIDS team. Although not easy to quantify, this fight for survival was a frequent theme when workers discussed ways to reduce stress levels. One AIDS social worker said,

> I don't know how to describe it; it's just a different sense of bonded-ness and helping each other. You're bonded (with staff), so if you need a favor or if they know you're out sick, you know your floor will be covered. Or if they pass you on the floor and say, 'What's the matter?' you take five minutes off to say how you are coping today."

Understanding, trust, and camaraderie appear to be the glue in this bonding.

The majority of AIDS social workers cited such bonded peer support as an important factor in successful coping and used it as a way to ventilate, emote, and problem-solve. "It's not just up to me. We make team decisions. I then feel like I don't need to do this work alone."

Sometimes the bonding with their peers is personal: "I share personal stuff with co-workers and have made some friends." Sometimes professional: "I am particularly helped by people at work; they reduce my stress the most. It's generally with people who know what's going on. I find that to be a relief." But both types were identified as helping reduce stress.

Perhaps team members were identified as supports because they "understood" as others could not. "I feel supported by my peers. I feel comfortable with them." Another said, "We work in specific teams. I feel we have a very supportive way of working with each other. It definitely helps in doing AIDS work." Another stated, "I started to become close with my co-workers--to talk more. My stress decreased and I started to feel better."

Bonding also helped staff to deal with the painful experiences inherent in working with AIDS patients.

> A team which is very close-knit and is willing to talk about the stress of working with people who are ill or dying, or just the willingness to talk about how painful it can be is one of the things that has been extremely helpful.

The trust and "knowing what it's like" to do AIDS work are the root of these strong bonds. "When I'm at work I have a few colleagues who I like and trust. I talk to them about whatever I am feeling. My office mate is very supportive; in fact, we have therapy every day." Another exclaimed, "I feel supported by my colleagues—no matter what!"

The bonds described by study subjects clearly transcended disciplines. They described bonds with all members of the AIDS team, regardless of their role. As one social worker stated, "I feel a strong connection to the RNs and MDs. I feel we have a very supportive way of working with each other. It helps in AIDS work."

The bonds created between AIDS providers were called a means of replenishment, by one respondent, "*I get replenished by my co-workers*." Other reasons given for seeking the support of co-worker were: a way to feel less isolated in their work, to get concrete assistance, to receive emotional support, to share feelings and to relax by joking. Thus, peer-type social support was found to be a primary self-care mechanism for AIDS staff, and was identified as an effective method to keep stress at a manageable level and to maintain staying power in AIDS work.

Supervisory Relationships

The supervisory relationship was viewed by AIDS social workers as integral to successful coping. Whether the relationship was negative or positive it strongly influenced worker retention.

Respondents who had a good working relationship with their supervisors clearly stated this aided them in coping. Feeling supported by their manager, as well as feeling understood, was seen as essential ingredients in coping with AIDS-related stressors. "I get excellent supervision. I talk about how I feel and share my personal struggles."

Supervisors were described as "running interference" in negotiating work struggles, administrative battles, or turf wars between providers on the interdisciplinary team. Sometimes good clinical supervision meant help on cases or monitoring work assignments (i.e., caseload size, negotiating bureaucratic factors).

Supervisors were described as either a valuable source of support in reducing workload stress or as a source of frustration, adding to feelings of cumulative stress. "Good" supervisors were those who understood the need to keep manageable caseloads, combining clinical work with much-needed concrete services (arranging for home care, insurance, housing). Such supervisors were seen as sensitive to the needs of staff and aware of the importance of how such management could reduce stress. Social workers also saw this sensitivity to work stressors as belonging to the supervisors' role.

Positive qualities identified for a supervisor were objectivity, listening, understanding, and allowing flexibility in the use of time off.

> I asked for some time off and was told just to take it because "I know how hard you work." That is respecting my "personhood" and saying to me, "You are valued and your work is appreciated." That in turn helps increase feelings of your self-worth and reduces your stress.

Additionally, practical, ethical leadership was described as the type of management necessary to reduce stress in a bureaucratic environment.

One individual described their supervisor as the center of their support system. He or she said, "My supervisor has been a magnificent support system. They have been a role model, teacher, friend, and supervisor all in one and had a really good balance of all those qualities." In some cases the supervisor carried a caseload. "Our supervisor is a part of our team. They set the tone for the profession and the respect we get." One supervisor answered how they saw their role, "I believe as a supervisor that it's my responsibility but I am not anyone's parent. I believe it is a supervisory relationship because I am giving them work and I need to set up an environment that they can work in; a supportive one where they can do their work."

A few study participants described their relationships with their supervisors as negative and demoralizing. Increased caseloads and bureaucracy were viewed as huge stressors, especially because of the perception of lack of supervisory support. One person pointed to this lack of support in their work environment as a reason for being unable to continue to work with AIDS patients. "As a social worker, I don't feel my supervisor adequately represents our interest in the AIDS Center." Without respect and available, non-judgmental management, workers expressed increased feelings of stress and low morale. Most respondents saw their supervisor's traits and their relationship with their supervisor as important factors in workers' coping ability. More than one stated this relationship was crucial to their overall ability to cope with the work. One social worker described the support received from their supervisor as providing a way to "bounce back" from feelings of burnout.

Thus, the relationship between AIDS social workers and their supervisors was found in this study to be a key factor in coping and implied reciprocity in helping to create a healthy work environment. If the supervisor assumed a role as a buffer to the stressors of AIDS work, workers saw them as very effective coping aids. When the relationship was strained or described as unsupportive, it added to the stress of the work. Hence, the role of the supervisor is pivotal in attracting, retaining, and supporting experienced staff.

Support Group Availability

Staff support groups were noted as being helpful within the context of a stressful job, with the availability of one seen as the organization taking an active role in providing organized support to staff. In a setting where no such group existed, one worker said, "There could be more organizational focus on the topic of *replenishing people* and helping them in terms of the work." They cited a staff group as one thing that could show workers the organization was interested in maintaining staff and avoiding burnout.

Most social workers thought a support group with an outside facilitator or leader should be available for them. Availability of such a group would somehow acknowledge management understands the difficulty of AIDS work and concern for workers' well-being. One respondent who participated in a support group said, "Sometimes we come up with a way of handling something. I find it helpful, because the group really 'jelled' the staff, at least those who came."

One person thought support groups for staff should be mandatory and offered on a regular basis. Others described support groups as a means of providing encouragement, and helping one feel less isolated.

A social worker from one organization which had just started a support group for staff described the group this way,

> The group is more for job stressors, not patient stressors. It's not like "I can't handle this patient." It's more the bureaucratic process that they've set up. The way the case management system works it makes it bureaucratic and impersonal. I think they are saying it is human behavior, but it is really classically organizational theory. You can't function that way as a social worker.

Humor

In the stressful environment of AIDS work, health care workers frequently use humor to relieve the pain of watching patients deteriorate and die (Fry & Salamah, 1993). Humor also helps form substantial bonds between providers, who often depend on each other for support and coping.

Social workers in the present study clearly articulated the roles of humor in their jobs. Humor was seen as a technique for coping with difficult situations with peers, team members, supervisors, and even patients. As one social worker said,

> Humor is just great. I think it really makes things light-hearted and takes the edge off and as long as you understand where it's coming from, and that it doesn't mean that nobody cares about the patient—it is basically a release. It is a way to take the pressure off and lightens up a difficult situation.

Participants describe humor as a unifying experience that connects people on another level. It was an essential coping tool.

Another social worker who saw humor as an essential self-care technique said "I love to laugh; it's the best thing I learned to do." While the use of humor in AIDS work serves multiple purposes, it is often initiated by the leaders of the team, who "set the tone" for the group. If management supports the use of humor, staff is more comfortable with it and many reported the benefits it had in relieving stressful situations.

As one staff member put it, "Humor is a tool, not just for us, but for patients. In our program, I think the tone is set up by the medical director and social work manager because they both have a great sense of humor. It's a balance thing."

One person thought humor was mainly used to blow off steam and that it generally worked. Another respondent described a situation with their student intern. "She used a technique (humor) and was wondering if it was OK. I said, 'its great' and what happened was the patient really opened up afterward."

Flexibility and Autonomy

The ability to have autonomy in one's work, as well as flexibility in how they did their job was reported as helpful in coping by study participants. As one worker said,

> Having an ability to come in late, stay late, and take a couple of hours off during the day and knowing my primary back-up will cover for me is important. It's the autonomy combined with a sense that I have someone available to help if I ask for it. For example... my cat died and my primary covering worker was out on leave, and yet there was no question and no consequence to my saying, "I need to take two vacation days."

When study respondents identified being overwhelmed and developed a stress management plan, some reported they had no control over implementing it.

Respondents stated flexibility depended largely on the supervisor, who often acted as a buffer to the larger bureaucracy. However, they reported some workplaces as being unable or unwilling to provide needed flexibility.

> If I have had a day that I haven't even had a lunch hour and at 4:00 p.m. all my patients are seen and, you know, there's nothing left to do I should be able to walk out the door. But, I have to sit here and clock out at 4:45 PM. And if I didn't get a lunch hour and I say that, they'll say, 'Well that's your fault.' If something was going down at lunch hour, they don't like you to take time after 2 p.m.and that's so impractical.

Flexibility to take time off for a professional conference was also reported as being both professionally and personally beneficial. When time was allotted for staff to attend continuing education, it helped them get away from day-to-day interactions, while staying informed about professional issues relevant to their jobs. Many educational seminars and conferences are directly related to care issues and provide valuable information on how to work with some of the organizational and emotional stressors of the job.

Self-regulation and Feelings of Control

In addition to receiving support from good team work and supervision, several respondents reported self-awareness as another aspect of self-care. The themes of being aware and in control, of self-regulating stress levels, and ultimately, of avoiding burnout, were seen as within the purview of the individual worker. As one stated, "It's not only the ability to be self-aware, but also to recognize your own stressors and work out a stress management plan." Although the organization was seen as important in helping staff implement self-care, as noted earlier, many social workers assumed some aspect of responsibility, whether they were able to avoid burnout or not. One respondent said, "It's a choice to be here and even if I ever got to the point or I felt dissatisfied and it was on a regular basis or over a period of time, I think (hope) I would go and find something else."

Feelings of having choices and being in control of how they managed their stress were described as requiring some personal attention; i.e., knowing when to take time off, balancing work and home life, and managing their own stress-buffering techniques. "As I think about my work," one social worker commented, "I think in terms of replenishment. I do think you need to make sure you take care of yourself. That works for me. Remembering it more and more, I think, helps me to keep working here."

Self-regulating how much is enough in order to achieve balance in one's life, and to allow time and energy to engage actively in self-care, was a common theme for many respondents. One social worker who was HIV positive stated, "I know this disease seven days a week, 24 hours a day. I do get burned-out, but it's only temporary", admitting also the need to limit HIV work, especially AIDS volunteer activities outside of their job.

Time Off

Study respondents reported one of the most valuable ways to regain their emotional balance was to take time off from their jobs. Whether weekends, vacations, or personal days, time off was described as a critical factor for rejuvenating themselves.

For those subjects who questioned their ability to keep doing AIDS work, time off seemed to be a major factor in restoring balance. One social worker who confided she had been having significant problems coping said, "I took a break, rested, and stayed with my family. I didn't talk about work. In fact, I totally forgot about work and I came back feeling good."

Respondents seemed to be very aware of the restorative effects of time off and said they scheduled it to avoid burnout. "I take time off. I like taking time off. We have comp days and I look forward to this time." She added this prevented her from getting to the point of not being able to cope. Another individual saw weekends as her time to gain perspective, which helped keep her stress at a manageable level. "I think it gets you out of the space and it helps to give you a better perspective and you recognize you'll be back in two days. You can sort of think about what's been going on and re-energize yourself."

At some point many said you need to "turn work off." One person described it especially well.

> I try to identify with what the stressors are and then I have to divorce myself from it for a short period of time in order to look at it and not allow it to take over myself. I think in my career, whatever the stressors are, you can't let your career take over your own life and you have to keep a tight check and a strong balance on your down time and there isn't a lot of it. So I make sure to get the most of the weekends and evenings when I'm not at my job.

Work-Life Balance

Balancing one's time and energy between work and home life was described by study participants as having a mediating effect on work stress. One respondent felt it was particularly important for people working in AIDS. "You can't let your career take over; you need to keep your work at work." Setting limits and not taking work home, either physically or emotionally, were seen as successful ways to remain balanced. Being realistic about balancing work and home life and viewing it as an ongoing process were also reported as essential in maintaining a healthy work perspective. One worker said, 'I am still trying to find ways to cope. I am paying more attention to the home-front, my wife, and my kids." Another responded, "I am now more realistic about balancing (work and home life) and am doing it effectively. It's a constant effort."

The main finding in this study regarding time and self-care was, "Leave work at work", although this was said in different ways. "I limit my scheduled appointments and take control over my work." "I switch work off, step away, and let go of it." "I make order out of other parts of my life." One subject stated, "I have significant interests in my life especially my family. I go home and forget about work. It's taken me a couple of years to be able to do that." Another social worker addressed this by saying, "I think I am able to do this by having some other significant interests in my life that I am connected to, as well as to my family. I live in Brooklyn so I leave here and really do feel separated. When I get home I just feel that it's my place and I feel connected to my community."

Some respondents stated they kept balanced by having a lot of other interests in their life. However, some participants said these interests could become stressors and this seemed to exacerbate the stress they were already experiencing. "Home stress on top of work can push me over the edge."

Therefore, the balance between home and work was reciprocal, but delicate. One person tied a successful balance between home and work to their supervisory relationship. "I have ample time to discuss my caseload and my feelings in regard to my caseload or just feelings about life and work (good and bad) and what feels great, or gets me down." The majority of respondents cited their relationship with their supervisor as one of the major factors in maintaining emotional resilience and being able to "leave work at work".

Thus, the balance between work and home is more successful with supervisor support, but is still a challenge. However, those able to negotiate it describe being less stressed.

Overall, there was a perception by most respondents interviewed in this study, balancing their home life and work life required self-care as well as a supportive work environment or supervisor. Self-care was described as within the individual's control. "If I can't identify it (stress), then I may fall into a really bad pattern or it may bring me down if I can't begin to look at it on my own." Another reported, "I can't rely on other people to notice when I am stressed out. I have to be able to identify it so that I can reach out and get what I need to take care of it (myself)." And another, "If the rest of my life is in order I can deal with the work stressors." For the majority, the best self-care was being able to know when to take time off. Vacation time and personal time were described as very important in keeping work stress manageable. Thus, a combination of work life and personal supports were viewed as an effective means of coping.

Therapy

Many participants in this study reported seeking individual therapy in addition to the help of their clinical supervisors in order to cope with their job stress. One said, "I sought therapy for both emotional support and clinical supervision. It allowed me to understand the behavior of patients and co-workers to enable me to work more effectively with both." There seemed to be a relationship between feeling one's clinical supervisor was not meeting their needs and starting or staying in therapy.

A few participants used therapy intermittently or when stress threatened to overtake their personal balance. "When I get overwhelmed, I call my former therapist. She puts me back on the right track. I needed to talk most to ventilate." Some described their relationships with their peers as being a kind of group therapy every day.

At times, there was overlap between one's individual therapy and social support (including a work support group), which seemed to relate to previous or current mental health treatment. Those staff wanting more of a boundary between their professional and personal lives sought therapy for their emotional renewal. Whether or not one shared their feelings at work depended on the level of trust in colleagues and the supervisory relationship.

Relaxation Techniques and Hobbies

Complementary therapies were also a method participants in this study reported using to cope with their AIDS-related work stressors. Yoga, massage, and acupuncture were mentioned by several respondents as techniques for stress reduction. There was some overlap between those who reported physical activity as a source of coping and those who also used complementary therapies. In one case, the subject tried acupuncture when time constraints prevented aerobic activity. Massages were another form of relaxation used by these workers as a conscious practice in stress reduction. Other reported relaxation techniques included self-talk as a cognitive response, deep breathing exercises, and yoga.

Hobbies were also found to be a popular coping technique. One respondent said, "My garden helps me cope." Such activities ranged from stripping furniture to going to the movies. Reading, cooking, and outdoor activities were the most frequently mentioned activities to effectively deal with their work stress.

Regardless of the type of activity, relaxation and hobbies were strategies used as conscious self-care techniques to reduce the stress involved in AIDS work and useful tools that helped maintain the work-life balance.

Physical Activity and Recreation

Physical activity, particularly, was reported by study respondents as invaluable in personal replenishment. Regular exercise was viewed as a way to decompress, take care of oneself, and to protect against depression. The strong need to work out their stress through physical activity seemed to be due to their recognition of its benefits. "I work out religiously to get rid of my stress; I lift weights and do aerobics."

In some cases, participants reported increasing their activity as their stress level increased. "I go to the gym. I find myself going a lot lately. I think sweating helps." "The treadmill is the best thing for me." Several described their activity, whether going to the gym, running, or swimming, as compulsive. "I swim regularly . . . no – *compulsively*." This worker had started to exercise frequently after surgery and viewed the activity as a way to take better care of herself. For some, physical activity was used as a protection against depression and inertia. "Exercise for me is a *harbor from the day*." Another said, "I go to the gym every night." Many said the gym was also a source of social support, a place to meet friends and an incentive to get out of the house.

The majority of study participants were found to use physical exercise or recreational activities to reduce their stress level and that, on an emotional level, this was tied internal replenishment. As one worker stated, "I see exercise as a way to take care of myself, an inner replenishment that is critical to doing this type of work." Looking forward to their routine physical activities after work was one way social workers sometimes made it through the day. "I ski, skate, and bike. I look forward to it all day."

Whether described as a "safe harbor," compulsive need, or a guard against inertia or social isolation, physical activity was clearly defined in this study as a major source of stress reduction for social workers who work in the AIDS field, who used it to relax, meet friends, and decompress from their physically and mentally demanding work.

Conclusion

AIDS social workers reported a wide array of self-care behaviors and activities which they use to replenish themselves from their stressful occupations. Self-care tactics, which include physical, emotional, mental, and spiritual outlets, were found to be the major strategy AIDS caregivers used to alleviate stress and to continue their work.

Relationships were the most frequently reported source of refreshing or sustaining subjects' mood, energy, or positive outlook, whether with family or friends or with co-workers and supervisors. Peer support, especially for those who described an emotional bonding with someone at work, was a significant source of replenishment because peers could most closely "understand" the pressures of the work environment and, thus, "validate" the worker's feelings. Supportive supervisors were especially appreciated, as were formal organizational supports such as appropriate training, sensitive scheduling and workload assignments, staff or team talk sessions, memorial services, and other on-site mechanisms to help workers defuse or to appropriately channel their job stress.

In the work environment particularly, but also outside it when discussing the pressures of work, respondents frequently used humor," gallows humor", as a coping strategy to defuse stress, as well as to bond within their work teams. Even with patients (and in some cases, *especially* with patients), the use of humor allowed workers to develop very close relationships with dying patients, yet help them to live as positively as possible while planning for whatever their future might entail. Humor thus served to "dislodge" the intensity of these serious and constant realities.

Physical activity and spiritual beliefs or affiliations were the most frequently reported individual techniques of replenishment. A majority of study respondents reported their spirituality was effective in helping them cope. Some found this renewal in organized religion, where the liturgy, creed, or church communities provided them with emotional or social support. Others simply found support in their personal beliefs and practices, their philosophy of life, or their sense of social consciousness and dedication to helping others in practical, hands-on ways.

Maintaining a balance between work and home lives was also reported to be an essential element of self-care. Taking time off, leaving the problems of work at work, and keeping physically active in off-hours were found to be particularly effective coping strategies. Some respondents used exercise, yoga, or meditation routines to unwind, describing themselves as compulsive about doing these activities because they were so effectively renewed by them. Physically working out their stress was how many maintained what they viewed as a balanced life.

In general, study subjects expressed a strong sense of responsibility for their own replenishment, and awareness of which techniques were most effective for them. They also acknowledged having direct control over much of their caregiving effectiveness. Perhaps for this reason, study respondents were often particularly distressed by bureaucratic barriers to good patient care. Because they worked hard to keep their own attitudes and priorities balanced in order to deliver the care their patients need and deserve, they seemed to believe the organization should certainly be willing to "do the same" by supporting them with appropriate policies and work assignments.

CHAPTER VIII

SUMMARY AND FUTURE RECOMMENDATIONS

Introduction

The purpose of this study was to explore how AIDS social workers coped, their response to job-stress, and whether individual or organizational interventions kept them replenished. I also sought to determine if there was a continuum of responses from coping through burnout. The concept of replenishment was investigated to determine whether individual coping mechanisms or organizational support systems could help AIDS social workers maintain their job satisfaction and remain in AIDS hospital social work.

Understanding how social workers cope and what the organization can do to keep them replenished has yet to be studied. Exploring the concept of replenishment is a beginning step to learn what factors contribute to maintaining experienced AIDS social workers. Individual resilience or hardiness has been studied in relation to stressful work environments. Yet, the role of the organization, including formal and informal supports, in replenishing staff is unknown.

In this study, questions were designed which explored why social workers chose AIDS work, what they expected in this job, and whether or not their expectations were fulfilled. The next section describes these experiences and their impact on their job satisfaction and coping capabilities.

Choosing AIDS Work

Social workers choosing to work in AIDS had both personal and professional reasons for their decision. There were several workers with close ties with the LGBT community. These workers discussed an overlap between their personal lives and work lives. Previous losses of friends, lovers, and family members from AIDS were more evident in this group. This created more difficulty dealing with all the loss at work. Personal losses were referred to in the interviews and their impact on how they coped with patient deaths. Additionally, these workers had more problems with managing a work-life balance since many of their activities outside of their job included AIDS-related community involvement through political activism, volunteering, or caring for friends with AIDS.

It was interesting that several staff saw choosing to work in AIDS as a form of self-protection. For some, it was related to having access to the most technical, up-to-date information. A few others referred to their own potential risk of becoming HIV-infected and believing doing this work could protect them in some way. Magical thinking was one way this was described. Another belief was that remaining uninfected would be a reward by doing this difficult job.

Professional reasons for choosing AIDS work was for some social workers a microcosm of all the reasons they entered the social work field. Working with illness, poverty, stigma and discrimination, substance abuse, and diverse populations embodied their work in AIDS. For others, doing work that was at the cutting-edge of medicine was very exciting to them. They discussed the challenges and rewards of this work and felt the former would be outweighed. Some social workers thought this work would enhance their professional development and career opportunities, given it was a new field with a good potential for growth.

For most, personal and professional reasons were both cited. There were no differences in coping or thoughts about leaving AIDS work based on the reasons selected for choosing AIDS. Even for the two respondents who stumbled into it, there were similar answers. Whether the reasons were personal or professional, both groups appeared to have the same commitment and staying power in AIDS.

The one worker who divulged their HIV-positive status felt similarly that it would be a way to be involved in AIDS work. Although they were already HIV positive, they felt that doing this important work would somehow protect them from the progression of the disease.

Another expectation of AIDS social workers was they would have long-term, intense relationships with their patients. Some anticipated the death and dying work as a positive expectation. Yet, with AIDS becoming more of a chronic illness, there are fewer hospitalizations and more community-based care. Resources for people with HIV/AIDS are also becoming scarcer as the number of people infected increase and longer timeframes of care and services are required. Hospitalizations are now of shorter duration as diagnostic relations groups (DRGs) and managed care restrictions reduce the number of days in the hospital, again creating less direct time with patients. This is a concern since what seems to replenish AIDS social workers the most is direct patient care.

What seemed more relevant to how social workers responded to stress and coping was their expectations in entering AIDS work. For most, there was an expectation of extensive social support from the team and peers, given the known job-related stressors. Lack of organizational or supervisory support was experienced as being thrown into a "sink or swim" situation. Staff felt responsible for finding their own support system. This was also true when team members were unsupportive. Lack of administrative structure, potential re-structuring, and real or threatened layoffs were experienced as a personal and professional failure. These unfulfilled expectations left staff angry and disappointed, and were experienced as "left holding the bag." Unfortunately, this type of chaotic work environment can set up an "us/them" mentality (management versus staff). In the recruiting and hiring process, realistic expectations that are verbalized between the supervisor and worker can help to diminish unfulfilled expectations and the negative stress associated with them.

Organizational Stressors on AIDS Social Workers

Organizational stressors were described as "low points" by participants in this study. Diminishing resources, increased managed care demands, facility reorganization, fear of layoffs, and decreased timeframes in direct patient care, especially in length of hospitalizations, all were found to negatively impact job satisfaction for these workers. In fact, organizational stress, in conjunction with AIDS job stressors, created an emotional burden for workers that threatened their effective coping and replenishment, as well as their desire to continue to do this work. Staff who experienced significant organizational stressors without an adequate support system, more frequently discussed leaving AIDS work. Also, personal/professional autonomy and scheduling/caregiving flexibility were found to be key factors in maintaining a positive work environment. Support from one's supervisor and the supervisor's willingness to "run interference" within the larger organization were important and a hallmark for successful coping.

Several metaphors were used by respondents to describe how stress impacted their job performance and ultimately their ability to cope. The cycle typically described was one of fatigue and rejuvenation, a process of depletion and replenishment. When depleted, social workers described themselves as going through the motions or working in a perfunctory manner. Becoming depleted was tied to chronic high levels of stress without adequate personal or professional supports. In addition to negatively impacting their job satisfaction, many internalized their job stress, i.e. depression and self-doubt, while others used a process of externalization, i.e. anger or leaving AIDS work.

The Rewards of AIDS Work

The question originally posed in the work of Strug, Grube, and Beckerman (2002), "Do the rewards of HIV/AIDS social work remain sufficiently satisfying to attract new practitioners to the field and prevent practitioners from leaving?" The answer, according to the findings of my study, is that the rewards of direct work with patients and families are what keeps them replenished. Working with patients throughout the course of their illness, even in the final stage of life, and perhaps, especially then, is the high point of their work. Respondents described feeling respected and appreciated for doing this important work. In fact, several respondents felt that in their role with patients they were viewed as a part of the family. They believed that in doing AIDS work they were making a difference in peoples lives, and at times, their deaths. For some, helping patients maximize the quality of life issues was replenishing.

Others found helping patients die a "good death" as most satisfying in their jobs, that is helping patients to define how they wanted to die. Clinical issues such as deciding when "enough was enough", i.e. when to terminate aggressive treatment, helping patients accept death as a natural process, and allowing them to die with dignity were all cited as major rewards of working with AIDS patients.

Another concept which emerged from the research was that of the "special" patient relationship. All participants identified at least one special patient relationship. In most cases that person had died, but was memorialized in stories and memories. Precisely what had created this becoming a special relationship was unique to each individual social worker and not clearly defined in terms of what characteristics made that person special. Yet, it was obvious in the responses certain patient relationships were more significant than others. Defining the parameters of what creates this special relationship is a topic for future research and might shed light on the subtleties of social work care in terminally-ill patients useful to other aspects of the profession.

Self-Care

The findings of this study conclude that coping with job-related stressors and avoiding burn out require a combination of self-care activities and organizational/co-worker support. Social workers caring for people with AIDS were able to articulate the multitude of stressors which impacted their work. They were also able to identify the beliefs, behaviors, and self-care activities which helped to replenish them. Ultimately, the majority of respondents believed they were responsible for their own emotional and physical well-being. Yet the combination of both individual and organizational intervention strategies was the most effective method in keeping participants replenished.

Spiritual and religious beliefs and practices were reported as a major form of coping and replenishment. Respondents differentiated between spiritual and religious beliefs; however, all believed in the concept of a higher power. Feelings of comfort and spiritual guidance were seen as protective or buffering factors that help to reduce stress and maintain resiliency. Even the social workers who stated they had difficulty coping with work stress, reported feeling re-energized through spirituality and religion. Praying, attending services, and maintaining a sense of community support through church or spiritual group activities were viewed as reducing stress and helping them to cope successfully, especially in their work around death and dying. Although helping patients die a "good death" was for some replenishing, it also was a source of a great deal of stress. Spirituality/religion helped respondents deal with their grief. Their religious community aided in comforting them and became an important source of ongoing emotional support.

Social support provided through relationships with family and friends was also found to be a major source of self-care for study respondents. Maintaining a balance between work and home life was achieved through this support. In addition, the value of co-worker support was described as a key factor. In this study, the responses around social support were similar to those of Wade and Simon (1992), which described the concept of survival bonding. Whether shared decision-making, ventilation, tangible aid, or emotional support, AIDS social workers highly valued co-worker support.

Supervisory relationships also were found to play an important role for AIDS social workers in maintaining a work/life balance, as well as buffering organizational factors contributing to stress. The availability of a flexible, autonomous work setting which encouraged time-off and provided institutional recognition and support, such as support groups, were also important factors in both job satisfaction and coping. Social workers who perceived themselves as having control over their work and having good relationships with their supervisors were better able to self-regulate and cope successfully.

Humor in the workplace served as a coping tool for study respondents, especially when it was accepted and modeled by leadership. Because AIDS work involves discussing subjects considered societal taboos, such as death, sex, and drugs, humor provides a mechanism to bypass discomfort with these subjects, to laugh, share, and vent feelings with fellow staff members. The use of humor in high stress jobs, such as emergency services and critical care offers a mechanism to decompress from the stress, as well as to bond with fellow co-workers.

The use of humor in high stress patient care areas, such as AIDS, was reported as a coping mechanism for staff. Additionally, in the case of AIDS social workers, the use of humor with patients and their families also provides the bonding necessary for effective patient care. Humor provides a way of lessening the intensity of needed discussions on the serious and constant realities of the disease, as well as planning for future eventualities. The type of humor often used is referred to as "gallows humor." According to Kuhlman (1993), it "offers an alternative cognitive set for coping with chronic stress" (p. 24). "Gallows humor flourishes when all else fails and there is no reasonable hope for an improvement in conditions" (p. 25). For staff working in a chronically stressful environment, "humor provides playful mastery when no work mastery is possible" (p. 26). In other words, when stress exists and cannot be avoided or controlled, gallows humor is an effective coping tool. It is also used when cognitive dissonance is present, i.e. helping to cure a disease (AIDS) when no cure is within their control. Bonding through the use of humor offers a supportive environment in which to work. Without it, coping and replenishment are often difficult.

Recommendations for Social Work Education

This research study was able to identify the job-related stress and coping mechanisms used by HIV/AIDS social workers. The findings indicate that self-care techniques and organizational interventions were found to mitigate the stress of AIDS social work and to help social workers stay replenished. This, in turn, allows for more resilient and experienced field work instructors.

Health care students require specialized training in key areas such as biopsychosocial assessments, disease processes and grief work. Hospital-based field work placements provide on the job experience to prepare students to work in a rapidly changing health care environment.

The findings of this study help to define the types of knowledge and skill building necessary to ready students for field work and eventual transition into the health care field. Training should focus on working effectively within a multidisciplinary team, self-care techniques which help in reducing stress, and clinical training which integrates mental and physical illness.

Social work education is faced with many challenges if it is to keep pace with the unrelenting changes in the health care environment. The transition from student to employee may be less stressful and more fulfilling after completing a year or more in a hospital field placement. According to one study (Pockett, 2003), the satisfaction of social work students completing field work training in hospitals greatly impacts their willingness to later accept employment in hospital settings (p. 3). Students gain valuable job experience working with very ill patients within relatively short time frames. In their discharge planner role, social workers address complex medical and psychosocial issues when working on inpatient units. Even ambulatory care social workers must address a wide variety of complicated physical and mental health needs, as more medical procedures once done in the hospital are now done on an outpatient basis. Students who are in field work placements, within a hospital setting, care for patients with acute, chronic and terminal illnesses. Psychosocial stressors such as substance abuse, family violence and homelessness complicate the biopsychosocial care and treatment of these patients. As care integration for physical and mental health move away from two separate entities, social work student training needs to incorporate theories, policies, and practice skills which address this broad range of clinical issues.

Similarly, diseases such as HIV/AIDS, where complications such as dementia, delirium, and major depression coexist with physical illness, social work education must develop both a knowledge base and practice skills which integrate physical and mental health care. Social work training that incorporates sexual health issues, death and dying/grief work, and work with addiction can better prepare social workers for future employment in HIV/AIDS work. Once hired, employees should receive on the job training, clinical supervision, and mentoring by peers. The proper foundation and specialized training can help to mitigate future job stress and the potential for burnout.

In addition, training in how to work most effectively within a multidisciplinary team can also be productive for students as they transition into the workplace. Skills which can be learned and then applied in a work setting include: how to assert your "voice" within a team, negotiation skills dealing with treatment differences, and how to advocate for a patient's right to self-determination.

Further, students can be taught both the need for and techniques of self-care which help them to manage job stress and to avoid burnout. Self-regulation for work stress was seen by respondents in this study as within their purview; taking responsibility for identifying their coping and replenishment techniques may be a factor in preventing burnout. Helping students to realistically address these difficulties and to identify ways to manage them in the classroom will eventually help organizations with retention of workers.

As noted in Ray, Nichol and Perritt (1987), "Due to a lack of preparation for coping with the emotional stress of human service work, many workers are unable to maintain the commitment and sense of caring which they originally brought to the job and often begin the process leading to burnout" (p. 6).

Recommendations for Research

Horsman and Sheeran (1998) found that "Caring for people with AIDS can be rewarding for health care workers but is potentially very stressful and more research is needed to identify particularly stressful factors, both at the organizational level and among individual workers, and try to prevent them or reduce their effects. The need for staff support must be established, and the effects of different types of support which require evaluation in order to promote the health for the carers" (p. 1561).

This current exploratory study was a beginning attempt to define and understand the concept of replenishment from the "voice" of the practitioner. Strug, Beckerman, and Grube (2003) report what social workers define as the stressors of working with HIV/AIDS patients, as well as the rewards which impact job satisfaction and their ability to cope. Another study (Pockett, 2002) explored reasons hospital-based social workers decided to stay with or leave their jobs. The decision to stay or leave is tied to stress, effective coping mechanisms, and the perceived rewards of their work. Over the years, the literature on burnout has provided a significant contribution to our understanding of how staff become physically and emotionally exhausted. Yet, less has been done to understand the individual and organizational factors which can help staff to avoid becoming depleted, or conversely, help them become replenished.

This research suggests that to counter a stressful job, such as working with AIDS patients, requires organizational supports, as well as a variety of self-care techniques. There were common themes which resonated for the majority of respondents. The results provide a beginning framework to further study the concept of replenishment. Although respondents did not report a continuum of coping ranging from burnout through replenishment, they used a metaphor of fatigue and rejuvenation to describe this process. Future research is necessary to understand whether this metaphor describes a process of depletion and replenishment as well.

In addition to studying the concept of replenishment, this study revealed a broad repertoire of self-care techniques reported by respondents which may provide interesting research possibilities. This study did not measure the quantity or quality of self-care methods used to cope, or whether organizational support or individual coping techniques worked best. Quantitative research studies using more scientific measures to determine which self-care techniques provide the essential buffering necessary to reduce stress, or their overall effectiveness in avoiding burnout, could be a next step.

Also, studies that determine whether resilience, hardiness or replenishment have similar or different attributes or meanings would further the research on coping and burnout in high stress areas, such as HIV/AIDS work. Other research topics worth developing are themes such as the "special patient;" what constitutes this relationship, the death of a special patient and its impact on staff, how social workers identify a special patient relationship, and whether this phenomenon exists only in HIV/AIDS work. The unpredictable death of a patient is described as a stressor whereas an anticipated death allows the opportunity to help the patient die a "good death." Further research could identify whether the stressor is the unpredictability of their death or the missed opportunity of helping patients prepare for their death.

Horsman and Sheeran (1998) state "The subject areas which are investigated need to be identified by in-depth qualitative studies which would emphasize the phenomenology of being a health care worker working in the context of HIV/AIDS. Too often, health care worker's own perspective appears to be lost by the manner which issues have been framed by researchers" (p. 1563). Practitioners working in tandem with researchers would be a positive next step in helping to answer some of these questions.

Integrating the voice of the practitioner with the methodologically skills of the researcher could be a powerful combination for future research studies.

Recommendations for Administrators

The work environment is an important factor in how AIDS workers react to job stress and on their ability to cope. In organizations which are inflexible and more bureaucratic, stress levels are high and job satisfaction low. As discussed in the review of the literature, this high demand work combined with low control/autonomy over their work, was found in this study to increase the risk of staff burnout and job dissatisfaction. Even in a bureaucratic setting, there are successful interventions which can act as a buffer to counter job stress. One of the most important of these interventions is a supportive supervisory relationship. The supervisor plays a pivotal role in terms of how stress is perceived. As found in this study, when relationships with managers were supportive and nurturing, workplace stress decreased. Workers who describe their relationships with their supervisors as positive had less stress and greater job satisfaction. According to Pockett (2003), a number of studies have documented the importance of the supervisory relationship on workers' level of job satisfaction. My study confirmed these earlier research findings.

A supervisor, who is trusted, respected and viewed as running interference for the worker within the larger system is considered a valuable means of support. The supervisor is often the catalyst to providing other formal supports, such as arranging for staff support groups and memorial services. The supervisor has the ability to pair workers in an effort to maximize informal mentoring and to encourage informal supports similar to that in survival bonding (Wade and Simon, 1992). The supervisor also facilitates the integration of staff into the larger organization. Previous research (Pockett, 2003) shows that job satisfaction is dependent on three variables: interdisciplinary team support and autonomy in one's work, interrelationships between professional aspirations and those of the institution, and the degree to which the worker is integrated into the hospital (p. 10).

In my research, several respondents identified their supervision as a major source of replenishment. This is especially true of supervisors who created a trusting, open, and supportive work environment. The supervisory relationship cannot be overlooked as a major form of stress or replenishment, depending on how they are able to balance their roles as administrator and advocate for staff.

Recruitment and retention of staff are also within the purview of the manager. According to my research, job expectations articulated clearly at the time of hire are a significant factor in job satisfaction. The greater alignment between anticipated job expectations and the realities of the job itself, the greater the likelihood of job satisfaction. Supervisors must make an effort to review what they expect from the employee, as well as eliciting from the potential employee what they expect from the job. As found in this study, this discussion can help to avoid job burnout and can lessen job dissatisfaction.

Cushman, et. al. (1995) reports human service jobs are associated with low pay, few promotional opportunities, and high work load demands. As a result, supervisors are limited in their ability to reward staff. Job recognition, work autonomy and specialized training are just a few ways available for managers to acknowledge and support staff.

Finding other avenues by which to create a supportive environment will greatly increase the likelihood of having productive and replenished staff.

The findings from this research study indicate that coping and replenishment are possible even in high stress areas such as HIV/AIDS work. In order to stay resilient and adaptable in the changing face of hospital social work, Pockett (2003) believes administrators and supervisors must address key factors which influence the retention and turnover of hospital social workers, namely job satisfaction, relationships with the organization, and the meaning of work. The findings of this study corroborate that belief.

This research study reaffirms the pivotal role of the supervisor in staff retention and job satisfaction. Avoiding certain pitfalls, i.e. lack of supervisory training, while modeling leadership that encourages work-life balance, time off, stress management and other self-care techniques can lead to successfully recruiting, retaining, and replenishing valuable, experienced HIV/AIDS social workers.

Conclusion

This chapter reviewed the major conclusions of this qualitative research study and discussed how the findings can be integrated into useful practices for social work educators, administrators, and researchers. The concept of "replenishment" is identified as a means to avoid depletion or burnout, and alternatively, if depleted, how to renew or restore a sense of wholeness or vigor. Organizational interventions in tandem with self-care techniques can successfully reduce the negative impact of chronic stress and ultimately may prevent burnout in social workers working with AIDS patients. This research focused on using the voice of practitioners as a way to better understand the stressors that deplete them, as well as the personal and organizational strategies which keep them replenished.

Appendix I

Interview Guide

Opening Statement

I am going to ask you some questions about your work in AIDS to help me understand more about the AIDS social work experience, including stressors and the way social workers cope. The interview will take approximately one your. All information from this interview will be used to gather information for a doctoral dissertation and will be kept confidential. Do you have any questions before we begin?

1. Can you tell me what made you decide to work in AIDS?

Prompts: Job opening, commitment to AIDS, knew someone with AIDS, career development, cutting edge, salary - other?

2. What were the two main things you expected in taking this position?

Prompts: Do job for one year, feel helpful, to be a part of a team, feelings of personal accomplishment like working with the terminally ill.

3 Were your expectations met? Please explain?

4. Can you tell me what the high point was in your work in AIDS?

5. Now, can you tell me what your low point was in your work in AIDS?

5a) Are there times that were worse than others? If yes, what characterized those times?

Prompts: Stress, role conflict, organizational pressures, bureaucracy, stigma, watching patients decline/die..

6. What are the stressors in your work in AIDS?

Prompts: High case loads, death and dying, patient population, administrative paperwork, over identification with patients.

7. How do these stressors impact your performance? Please explain.

7a) How do these stressors impact your job satisfaction? Please explain.

Prompts: Feel exhausted, withdrawn from staff or patients, increase in personal/relationship difficulties, use of drugs/alcohol, feel burned out, looking for another job, want to leave AIDS work.

8a) Generally do you feel able to cope with stressors or feel unable to cope with the stress from your job?

8b) How frequently if ever do you feel unable to cope?

8c) What do you do when you feel most stressed?

Prompts: Take time off, seminars, supervision, peer/team support

9. What do you feel are the two most important things that help you cope with this stress? Are there people activities or things that help you cope?

9a) Of these, which reduces your stress the most and why?

Prompts: personal: religion/spirituality, visualization or meditation, yoga, exercise, family/friends.

Organizational: Formal-support groups, bereavement group/memorial services, decreasing your caseload, .supervision, continuing education, co-workers.

10. Did you develop any significant relationship(s) with anyone at work that you feel helps reduce your stress?

11. Do you ever feel you are unable to keep doing this job? If so, how do you regain emotional strength?

Prompts: Time off, formal or informal social supports, personal relationships, exercise, taking care of oneself, spirituality, team support.

12. What keeps you in AIDS work?

Prompts: No jobs available, job security, working with patients/families, co-worker or other relationships, commitment to AIDS work.

13. Have you considered leaving AIDS work and if so, why?

Prompts: Unable to cope with stress, feelings of burnout, emotional exhaustion, grief overload.

14. What do you feel are the supports needed to help you reduce stress?

15a) Do you think there are things that the hospital could do to reduce the stress of AIDS workers?

15b) Does you hospital offer anything now?

Appendix II

Telephone Script
Recruitment of Participants

July 10, 1996

Hello, my name is Kathy wade. I am a social worker at Presbyterian Hospital and a doctoral student at Hunter College School of Social Work. I am doing a dissertation project on the stressors and coping strategies of hospital-based AIDS social workers.

I am calling to ask if you would be willing to be interviewed for this project. The interview will last for approximately 1 1/2 hours and will include questions regarding AIDS work, specific stressors, coping techniques and organizational strategies to help replenish AIDS social workers. Would you be interested in participating?

The information provided to me will be strictly confidential and be presented anonymously in the dissertation. No specific names or organizations will be named or be identifiable. You do not have to answer any questions you do not wish to answer. Do you have any questions about the dissertation, the interview or your participation? Thank you so much for your participation.

Bibliography

Balduck,R.J. (1996). "Social Worker Burnout in the Field of HIV/AIDS". Unpublished master's thesis. California State University: Long Beach. Masters Abstracts International, 34-06, 2235.

Barbour, R.S. (1994). "The Impact of Working with People with HIV/AIDS; A Review of the Literature". Social Science Medicine, 39(2) 21-232.

Beemsterboer, J. and B. Baum. (1984). "Burnout: Definitions and Health Care Management." Social Work in Health Care. 10(1) 97-109.

Berggren, T., M. Hane, and K. Ekberg. (1975). "Stress at Work: An Interactive Model for Work Environment Analysis." Occupational Medicine: Principles and Practice Applications. Chicago. Year Book Medical Publications, Inc.

Bennett, L.(1992b). "The Experiences of Nurses Working with Hospitalized AIDS Patients." Australian Journal of Social Issues. 27.125-143.

Bennett, L., D.Miller, and M.W. Ross (1995). Ed. L.Bennett. "Review of the Research to Date on Impact of HIV/AIDS on Health Care Workers." Health Workers and AIDS. Research, Intervention and Current Issues on Burnout and Response. Switzerland. Harwood Academic Publishers. 15-34.

Bennett, L.,M.W. Ross and R. Sunderland. (1996). "The Relationship Between Recognition, Rewards, and Burnout in AIDS Caring." AIDS Care. 8(2). 145-153.

Bennett, L. (1995). In L. Sherr. "AIDS Health Care: Staff Stress, Loss and Bereavement." Grief and AIDS. New York. John Wiley and Sons. 87-102.

Bennett, L.,P. Michie, and S.Kippax. (1991). "Quantitative Analysis of Burnout and Its Associated Factors in AIDS Nursing." AIDS Care. 3(2). 181-192.

Bennett, L., M.Ross, and M. Kelaher.(1993). Ed. van Dis, H. and van Donger. "The Impact of Working with HIV/AIDS on Health Care Professionals: Dimensions and Measurement." Burnout in HIV/AIDS Health Care and Support. Amsterdam University Press. 11-21.

Ben-Sira, Z. (1984). "Chronic Illness, Stress and Coping." Social Science and Medicine.

Bergman, A., A. West, and N. Lewiston. (1979). "Social Work Practice and Chronic Pediatric Illness." Social Work in Health Care. 4. 265-274.

Branner, L.M. and P.J. Albrego. (1981). "Intervention Strategies for Coping with Transitions." Counseling Psychologist. 9. 19-36.

Brown, L.K. and P. Stermock. (1999). "Emotional Reactions of Haemophilia Health Care Providers." Haemophilia. 5(2). 127-131.

Catherall, D.(1995). Ed. B. Stamm. "Coping with Secondary Traumatic Stress: The Importance of the Therapist's Professional Peer Group." Secondary Traumatic Stress. Lutherville,Maryland. Sidran Press. 80-94.

Centers for Disease Control. (1989). "Tuberculosis and HIV Infection: Recommendations of the Advisory Committee for the Elimination of Tuberculosis." Morbidity and Mortality Weekly Report. 38(14). 236-249.

Cherniss, C. (1980). Staff Burnout: Job Stress in the Human Services. Beverly Hills, California. Sage Publications.

Chateauvert, M. (1993). "AIDS Related Stress in Canadian Health Care Workers." Burnout in HIV/AIDS Health Care and Support. Amsterdam University Press. 53-60.

Coady, C., V.Kent, and, P. Davis. (1990). "Burnout Among Social Workers Working with Patients with Cystic Fibrosis." Health and Social Work. 5. 116-123.

Cobb, S. (1976). "Social Support as a Mediator of Life Stress." Psychosomatic Medicine. 38. 300-314.

Cushman, L.S., P. Evans, and P.B. Namerow. (1995). "Occupational Stress Among AIDS Social Service Providers." Social Work in Health Care. 21(3). 115-131.

Davidson, K. and Z. Foster. (1995). "Social Work with Dying and Bereaved Clients: Helping the Workers." Social Work in Health Care. 21(4). 1-16.

Dohrenwend, B., K.G. Raphael, S. Swartz, A. Stueve and A. Skodol. (1991). "The Structured Event Probe and Narrative Rating Method for Measuring Stressful Life Events." Handbook of Stress: Theoretical and Clinical Applications. New York. Free Press.

Doka,D.J. (1989). Disenfranchised Grief, Recognizing Hidden Sorrow. Lexington, Maine. Lexington Books.

Driedger, S.M. and D. Cox. (1991). "Burnout in Nurses Who Care for PWA's: The Impact of Social Support." AIDS Patient Care. 9. 197-205.

Dunkel, J. and S. Hatfeld. (1986). "Countertransference Issues in Working with Persons with AIDS." Social Work. 31(2). 114-117.

Edelwich, J. (1980). Burnout: Stages of Disillusionment in the Helping Professions. New York. Human Services Press.

Egan, M. (1993). "Resilience at the Front Lines: Hospital Social Work with AIDS Patients and Burnout." Social Work in Health Care. 18(2). 109-125.

Egan, M. and G. Kadushin. (1995). "Competitive Allies: Rural Nurses and Social Workers' Perceptions of the Social Work Role in the Hospital Setting." Social Work in Health Care. 20(3). 1-24.

Ell, K.O. (1985). "Coping with Serious Illness: On Integrating Constructs to Enhance Clinical Research, Assessment and Intervention." International Journal of Psychiatry in Medicine. 15(4). 335-357.

Evans, G.W. and S. Cohen. (1987). "Environmental Stress." Eds. D. Stokols and I. Altman. Handbook of Environmental Psychology. New York. John Wiley and Sons. 1. 571-610.

Ferrer, R. (1998). "Lymphadenopathy: Differential Diagnosis and Evaluation." American Family Physician. 58(6). 1313-1322.

Fry, W. and W. Salameh. (1993). Advances in Humor and Psychotherapy. Florida. Professionals Resource Press.

Flannery, R.B. (1990). "Social Support and Psychological Trauma: A Methodological Review." Journal of Traumatic Stress. 3(4). 593-611.

Furstenburg, A. and M.M. Olsen. (1990). Ed. K. Davidson. "Social Work and AIDS." Social Work in Health Care: A Handbook for Practice. New York. The Haworth Press. 689-711.

Garrett, C. (1999). "Stress, Coping, Empathy, Secondary Traumatic Stress and Burnout in Healthcare Providers Working with HIV Infected Individuals". Dissertation Abstracts International, 60 (04A), 1329. (University Microfilms No. AAG9925490).

Gimbel, R.W., S. Lehrman., M..A. Strosberg., V. Ziac, ., J. Freedman, ., K. Svicki, and L. Tackley, (2002). "Organizational and Environmental Predictors of Job Satisfaction in Community-based HIV/AIDS Service Organizations". Social Work Research, 26(1). 43-46.

Glaser, B. and A. Strauss. (1967). The Discovery of Grounded Theory. New York. Aldine de Gruyter.

Grube, B.,N.L. Beckerman, and D. Strug (2003). "Examining the Unique Stresses and Rewards of HIV/AIDS Work: Then and Now." Journal of HIV/AIDS and Social Services. 1(2). 5-20.

Gottlieb, B. (1985). "Assessing and Strengthening the Impact of Social Support on Mental Health." Social Work. 30. 293-300.

Gordin, C. (1987). "Face to Face: A Guide to AIDS Counseling." AIDS. 1(3). 183-188.

Gordon, J.H., C. Ulrich, M. Feeley, and S. Polluck (1993) "Staff Distress Among Haemophilia Nurses." AIDS Care. 5. 359-367.

Guinan, J.J., L.W. McCallum, L.Painter, J.Dykes, and J. Gold (1991). "Stressors and Rewards of Being an AIDS Emotional-Support Volunteer." AIDS Care. 3(2). 137-150.

Guzzo, R.A. and G.P. Shea. (2002). Ed. W. Sotile. "Introduction." The Resilient Physician. American Medical Association. xvii.

Henderson, L (2000) "The Knowledge and Use of Alternative Therapeutic Techniques by Social Work Practitioners: A Descriptive Study." Social Work in Health Care. 30(3). 55-71.

Honey, E. (1988). "AIDS in the Inner City: Critical Issues." Social Casework. 6. 365-370.

Horsman, J.M., and P. Sheeran, (1995). "Health Care Workers and HIV/AIDS: A Critical Review of Literature". Social Science Medicine, 41(11). 1535-1567.

House, J. (1981). Work Stress and Social Support. Reading, Mass. Addison-Wesley Publishing.

Itzhaky, H. and R. Atzmon. (1999). "The Role of the Supervisor in Training Social Workers Treating HIV-infected Persons in a Hospital." Social Work in Health Care. 29(1). 57-74.

Ivancevich, J., and M.T. Matteson (1983). Stress Diagnostic Survey. Houston. Stress Research Systems.

Jackson, S.E., R. Schuler, and R. Schwab. (1986). "Toward an Understanding of the Burnout Phenomenon." Journal of Applied Psychology. 71(4). 630-640.

Jamal, M. (1999). "Job Stress and Employee Well-Being: A Cross-Cultural Empirical Study." Stress Medicine. 15. 153-158.

Johnson, M. and G. Stone. (1987). Ed. D. Gillespie. "Social Workers and Burnout: A Psychological Description." Burnout Among Social Workers, New York. Haworth Press, Inc. 81-90.

Kadushin, A. (1999) "The Role of the Supervisor in Training Social Workers Treating HIV-infected Persons in a Hospital." Social Work in Health Care. 29(1). 57-74.

Karasek, R. (1979). "Job Demands, Job Decision Latitude, and Mental Strain: Implications for Job Redesign." Administrative Science Quarterly. 24. 285-308.

Karon, J,M, P.L.Fleming, R.W. Steketee, and K. M. DeCock. (2001). "HIV in the United States at the Turn of the Century: An Epidemic in Transition". American Journal of Public Health. 91(7). 1060-1068.

Kelly, B., B.Raphael, F. Judd, G. Kernutt, P. Burnett, and P.Burrows. (1998). "Posttraumatic Stress Disorder in Response to HIV Infection". General Hospital Psychiatry. 20(6). 345-352.

Kobasa, S. C., S. Maddi, and S. Kahn. (1982). "Hardiness and Health: A Prospective Study." Journal of Personality and Social Psychology. 42. 243-248.

Koeske, G. and R. Koeske. (1989). Work Load Burnout: Can Social Support and Perceived Accomplishments Help?". Social Work. 43(3). 243-248.

Klonoff, E.A. and D. Ewers. (1990). "Care of AIDS Patients as a Source of Stress to Nursing Staff." AIDS Education and Prevention. 2(4). 338-348.

Kobasa, S. (1979). "Stressful Life Events, Personality, and Health: An Inquiry into Hardiness." Journal of Personality and Social Psychology. 37. 1-11.

Lambert, V., C. Lambert, and H. Yamase. (2003). "Psychological Hardiness, Workplace Stress and Related Stress Reduction Strategies." Nursing and Health Sciences. 5(2). 181-190.

Leiter, M. and C. Maslach. (1981). "The Impact of Interpersonal Environment on Burnout and Organizational Commitment." Journal of Organizational Behavior. 9. 297-308.

Lincoln, Y.S. and E. G. Guba. (1985). Naturalistic Inquiry. Beverly Hills, California. Sage.

Lopez, D. and G. S. Getzel. (1984). "Helping Gay AIDS Patients in Crisis." Social Casework. 65(7). 387-394.

Mantell, J., L. Shulman, M.Belmont, and H. Spivak. (1989). "Social Workers Respond to the AIDS Epidemic in an Acute Care Hospital." Health and Social Work. 14(1). 41-51.

Maslach, C. (1982). Burnout: The Cost of Caring. Englewood Cliffs, New Jersey. Prentice-Hall.

Maslach, C. and S.E. Jackson. (1981). Maslach Burnout Inventory. Palo Alto, California. Consulting Psychology Press.

Maslach, C. and S.E. Jackson. (1982). Ed. G. Sanders. "The Burnout Syndrome in Health Professions: A Social Psychological Analysis." Social Psychology of Health and Illness. Hillsdale. New Jersey. Lawrence Erlbaum.

Maslach, C. and M. Leiter. (1997). The Truth About Burnout. California. Jossey-Bass.

Maslach, C., W. Schaufeli, and M. Leiter. (2001). "Job Burnout". Annual Review of Psychology. 52. 397.422.

Mervis-Itzkowitz, Phyllis. (2002). "The 'Double Nightmare' of Physical Illness in the Chronically Mentally Ill: A Qualitative Research Study of the Impact on Social Work Practice". Unpublished Doctoral Dissertation. City University of New York. Dissertation Abstracts International. AAT 3047245.

Miller, R. (1991). Ed. M. Amenta. AIDS and the Hospice Community. New York. Haworth Press.

Mor, V. and L. Laliberte. (1984). "Burnout Among Hospice Staff." Health and Social Work. 9(4). 274-283.

Moxley, D. (1989). The Practice of Case Management. Newbury Park, California, Sage Publishing.

National Institute of Health. "National Statistics on AIDS." Retrieved on Sept. 20,2003. http://www.niaid.nih.gov/factsheets/howhiv.htm.

Nesbitt, W.H., M.W. Ross, R.H. Sunderland, and E. Shelp. (1996). "Prediction of Grief and HIV/AIDS-related Burnout in Volunteers". AIDS Care, 8(2). 137-143.

Niven,C.A., and C. Knussen. (1999). "Measuring the Stress Associated with Caring for Clients with HIV/AIDS". AIDS Care. 11(2). 171-180.

Offerman, L. (1985). Ed. D. Keyes. Test Critiques. Vol. III.

Oktay, J. (1992). "Burnout in Hospital Social Workers Who Work with AIDS Patients." Social Work. 37(5). 432-439.

Paradis, L. (1987). Stress and Burnout Among Providers Caring for the Terminally Ill and Their Families. New York. The Haworth Press.

Parry, J. (1989).Social Work Theory and Practice with the Terminally Ill. New York.The Haworth Press.

Pasacreta, J. and P. Jacobson. (1989). "Addressing the Needs for Staff Support among Nurses Caring for the AIDS Populations." Oncology Nursing Forum. 16(4). 59-63.

Paton, S. (1992). "Stress and the Informal Caregiver." Focus. 7(12). 1-4.

Patton, M. (1987). How to Use Qualitative Methods in Evaluation. Newbury Park, California. Sage Publications.

Pearlin, L. I. and C. Schooler. (1978). "The Structure of Coping." Journal of Health and Social Behavior. 19. 2-21.

Peterson, J. (1991). "Social Workers' Knowledge about AIDS: A National Survey." Social Work. 36(1). 31-37.

Pines, A. and C. Maslach. (1978). "Characteristics of Staff Burnout in Mental Health Settings." Hospital and Community Psychiatry. 29(4). 233-237.

Pockett, R. (2003). "Staying in Hospital Social Work." Social Work in Health Care. 36(3). 1-24.

Polkinghorne, D. E. (1991). "Two Conflicting Calls for Methodological Reform." Counseling Psychologist. 19. 103-114.

Pomerance, L. and J. Shields. (1989). "Factors Associated with Hospital Workers' Reactions to the Treatment of Persons with AIDS." AIDS Education and Prevention. 1(3). 184-193.

Price, D.M. and P.A. Murphy.(1984). "Staff Burnout in the Perspective of Grief Theory." Death Education. 8. 47-58.

Ursprung, A. (1986). "Burnout in the Human Services." Rehabilitation Counseling Bulletin. 29. 190-199.

Ray, E.B., M.R. Nichols, and L.J. Perritt. (1987). Ed. L.F. Paradis. "A Model of Job Stress and Burnout." Stress and Burnout Among Providers Caring for the Terminally Ill and Their Families. New York. The Hawthorne Press. 3-28.

Reinhold, B.B. (1997). Toxic Work. United States. Plume.

Richmond, J.M., L. Rosenfeld, and J. Hardy. (1993). "The Social Support Survey: A Validation Study of a Clinical Measure of the Social Support Process." Research on Social Support Practice. 3(3). 288-311.

Rodgers, A.Y. (1995). "The Relationship Between Changes in Sexual Support and Adjustment to AIDS in Gay Males." Social Work in Health Care. 20(3). 37-49.

Rowe, W. S., G.E. Plum, and C. Crossman (1988). "Issues and Problems Confronting the Lovers, Families and Communities Associated with AIDS." Journal of Social Work and Human Sexuality. 6. 71-88.

Ross, E. (1993). "Preventing Burnout among Social Workers Employed in the Field of AIDS/HIV." Social Work in Health Care. 18(2). 91-107.

Rudestam, K. and R. Newton. (1992). Surviving Your Dissertation. California. Sage Publications.

Rutter, M. (1987). "Psychosocial Resilience and Protective Mechanisms." American Journal of Orthopsychiatry. 57(3). 316-331.

Ryan, C. (1991). "Where Do We Go From Here?" Social Work. 36(1). 3-4.

Schernoff, N. (1990). "Why Every Social Worker Should Be Challenged by AIDS". Social Work. 35 (1).

Schernoff, N. (1994). Ed. M. Sussman. "AIDS: The Therapists' Journey". A Perilous Calling: The Hazards of Psychotherapy. New York. John Wiley and Sons.

Schneider, J. (1982). "Self-Care: Challenges and Rewards for Hospice Professionals."

Schoen, K. (1992). "Managing Grief in AIDS Organizations." Focus: A Guide to AIDS Research and Counseling. 7(6).

Selye, H. (1993). Ed. L. Goldenberger. "History of the Stress Concept." Handbook of Stress: Theoretical and Clinical Aspects. (2nd ED.). New York. The Free Press.

Semmer, N. (1996). Ed. M.J. Schabracq, J. Winnubst, and C.L. Cooper. "Individual Differences, Work Stress, and Health." Handbook of Work and Health Psychology.

Sherr, L.(1995).Ed. L.Sherr. "The Experience of Grief: Psychological Aspects of Grief in AIDS and HIV Infection." Grief and AIDS. New York. John Wiley and Sons. 1-28.

Siefert, K., S. Jayaratne, and W. Chess. (1991). "Job Satisfaction, Burnout and Turnover in Health Care Workers." Health and Social Work. 16(3). 193-202.

Siu, O. and C.L. Cooper. (1998). "A Study of Occupational Stress, Job Satisfaction and Quitting Intention in Hong Kong Firms: The Role of Locus of Control and Organizational Commitment." Stress Medicine. 14. 55-66.

Skovholt, T.M. (2001). The Resilient Practitioner: Burnout Prevention and Self-Care Strategies for Counselors, Therapists, Teachers, and Health Care Professionals. Boston. Allyn and Bacon.

Snider, D., E. Salinas, and G. Kelly. (1989). "Tuberculosis: An Increasing Problem among Minorities in the United States." Public Health Report. 104(6) 646-653.

Soderfeldt, M., B. Soderfeldt, and L.E. Warg. (1995). "Burnout in Social Work." Social Work. 40. 638-646.

Sotile, W. and M. Sotile.(2002). The Resilient Physician. American Medical Association.

Spitzer, W. and K. Neely. (1992). "Critical Incident Stress: The Role of Hospital-based Social Work in Developing a State-wide Intervention System for First Responders Delivering Emergency Services. Social Work in Health Care. 18(1). 39-58.

Stav. A., V. Florian, and E.Z. Shurka. (1987). "Burnout among Social Workers Working with Physically Disabled Persons and Bereaved Families." Journal of Social Services Research. 10(1). 81-93.

Stein, E., K. Wade, and D. Smith. (1991). "Clinical Support Groups that Work." Journal of AIDS Nursing Care. 2(2). 29-36.

Stokols, D. and I. Altman. (1987). Handbook of Environmental Psychology. New York. John Wiley and Sons.

Strug, D.,B. Grube, and N. Beckerman. (2002). "Challenges and Changing Roles in HIV/AIDS Social Work: Implications for Training and Education." Social Work in Health Care. 35(4). 1-20.

Sze, C. and B. Ivker. (1986). "Stress in Social Workers: The Impact of Setting and Role." Social Casework. 141-150.

Tripodi, T.,P.Fellin, and H.Meyer. (1969). The Assessment of Social Research: Guidelines for the Use of Research in Social Work and Social Science. Illinois. F.E. Peacock.

Tyler, P. and Cushway, D. (1998). "Stress and Well-being in Health Care Staff: The Role of Negative Affectivity and Perceptions of Job Demand and Discretions." Stress Medicine. 14. 99-107.

Vachon, M. (1987) Ed. L. Paradis. "Team Stress in Palliative/Hospice Care." Stress and Burnout Among Providers Caring for the Terminally Ill and Their Families. New York. The Haworth Press.

van Rooijen, P. (1993). "Burnout: The Management of Our Search for Meaning in Life." Burnout in HIV/AIDS Health Care and Support. Amsterdam. University Press.

Wade, K. and E.P. Simon (1993). "Survival Bonding: A Response to Stress and Work in AIDS." Social Work in Health Care. 19(1). 77-89.

Wade, K., E. Stein, and N. Beckerman. (1995). "Tuberculosis and AIDS: The Impact on the Hospital Social Worker." Social Work in Health Care. 21(3). 29-41.

Wiener, L. and K. Siegel. (1990). "Social Workers Comfort in Providing Services to AIDS Patients." Social Work. 35(1). 18-25.

Yancik, R. (1984). "Sources of Stress for Hospice Staff". Journal of Psychosocial Oncology. 2. 21-31.

Yin, R. (1984). Case Study Research. Beverly Hills, California. Sage.